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## Improving occupational performance of people with a psychotic disorder post discharge from hospital

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IMPROVING OCCUPATIONAL PERFORMANCE OF  
PEOPLE WITH A PSYCHOTIC DISORDER POST  
DISCHARGE FROM HOSPITAL

MARY PATRICIA BIRKEN

THESIS SUBMITTED FOR A DEGREE OF DOCTOR OF PHILOSOPHY

INSTITUTE OF PSYCHIATRY  
KING'S COLLEGE LONDON

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# Abstract

Having a diagnosed psychotic disorder affects a persons' ability to participate in everyday life. An admission to hospital and deterioration of mental health are disruptions in life that can result in further skill loss and decrease in daily routine. The purpose of this study was to develop and pilot an intervention to improve occupational performance for people with a diagnosed psychotic disorder. The intervention aimed to address specific problems with occupational performance following discharge from hospital.

The study consisted of two stages. The first stage of the study combined four sub-studies to develop an intervention using best available evidence. A literature review of occupational performance and psychosis, focus groups with staff and service users, a systematic review of interventions and a literature review of models of occupational performance were completed to gather the evidence to inform the intervention. The second stage of the study used a quasi-experimental controlled study design to evaluate the developed intervention. A process evaluation was also carried out to assess the implementation of the intervention in clinical practice.

This study generated new knowledge regarding what is known about the problems of occupational performance following discharge from hospital and interventions to address these problems. A stepped intensity 16 week manualised intervention Graduating Living skills Outside the Ward, GLOW, was developed. The results of the pilot study indicated that participants in the intervention group, showed a greater improvement on the primary measure when compared to treatment as usual. Barriers to recruitment were encountered in this study.

Results of the pilot study showed that GLOW is an acceptable intervention to both service users and staff. The intervention was shown to have preliminary evidence of effectiveness. This indicates that GLOW merits further investigation to evaluate its effectiveness. The study recommends methods to increase participation of clinical staff in research.

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## Abbreviations

ADL	Activities of Daily Living
AOTA	American Occupational Therapy Association
AHPRN	Allied Health Professions Research Network
CPA	Care Programme Approach
EIT	Early Intervention Team
GLOW	Graduating Living skills Outside the Ward
ILSS-SR	Independent Living Scale Survey-Self Report
ICF	International Classification of Functioning, Disability and Health
MOHOST	Model of Human Occupation Screening Tool
MRC	Medical Research Council
OCAIRS	Occupational Case Analysis Interview and Rating Scale
OP	Occupational performance
OT	Occupational Therapist
PAMS	Placement and Management Service
PARRA	Promoting an Appreciation for Research-Related Activities
REIS-SF	Residential Environmental Impact Scale-Short Form
RCOMH	Research Centre for Occupation and Mental Health
RCT	Randomised controlled trial
STR	Support Time and Recovery
WHO	World Health Organisation

# Chapter 1 Introduction

## 1.1 Introduction

Psychotic disorders have a range of consequences. This study is concerned with the consequences relating to occupational performance, at a critical stage of transition of the person's life, following discharge from hospital. People with a diagnosed psychotic disorder have identified that taking care of oneself, having a sense of achievement, and enjoyment and fun in life are important to them and the maintenance of their health (Leufstadius et al., 2008). Therefore resuming these daily activities following discharge from hospital is important. This study aims to develop and pilot an intervention to improve occupational performance for people with a diagnosed psychotic disorder following discharge from hospital. This chapter provides an introduction to the area of study, the rationale for the study and an outline of the thesis.

## 1.2 Occupation

The focus of this study is occupational performance of people with a diagnosed psychotic disorder. In order to understand what is meant by occupational performance, the term occupation must be examined first:

*“An occupation is a group of activities that has personal and sociocultural meaning, is named within a culture and supports participation in society.”*(Creek, 2010, p.68)

Examples of occupations are cooking, playing a sport and attending a course. It includes all that we do during the day between waking and going to sleep.

Occupational performance has been defined as:

*“choosing, organizing and carrying out an occupation in interaction with the environment”* (Creek, 2010, p.89)

Occupational performance (OP) is therefore the act of carrying out an occupation and includes ability to carry out the occupation and expressing preference of occupation. People are occupational beings by nature, this is as a result of biological evolution and enculturation (Wilcock, 2006). Occupation is viewed as a component of health, by the World Health Organization(WHO), within the International Classification of Function (ICF) (World Health Organisation, 2001). The ICF has defined participation restrictions as a matter of citizenship and justice as well as health. The WHO and others in the public health fraternity have recognized that policies to improve a population's social experience and environment could be more important than improving individual health using medicine (Richards, 1999).

Involvement in daily life has been shown to reduce negative symptoms in a person with schizophrenia (Halford et al., 1995; Leff et al.,1994; Mairs & Bradshaw, 2004). It has also been acknowledged to contribute to quality of life (Bejerholm & Eklund, 2007).

There is a lack of agreed classification of occupations. Historically occupations have been described as consisting of three categories: self-care, leisure and work, however, these categories are subjective and an occupation may belong to more than one category. For example, a person may enjoy cooking for friends as a leisure occupation in addition to it being a daily self-care occupation. In the absence of an agreed classification of occupations, the study focuses on occupations involved in caring for oneself and home, and occupations involved in leisure both in home environment and community. This study does not focus on vocational occupations, as vocational rehabilitation is a specialist area with its unique and established evidence base.

The following definitions of leisure and self-care have been used in this study. The term leisure has been defined within the literature in many ways (Robinson, 1999) in this study, leisure has been defined as:

*“a non obligatory activity that is intrinsically motivated and engaged in during discretionary time, that is, time not committed to obligatory occupations such as work, self-care or sleep”*

(Parham & Fazio, 1997, p.250)

The benefits of play and leisure have been identified by people with mental health problems as directly reducing distress and providing a buffer against further stress (Shahar & Davidson, 2003). Leisure has also been found to support a renewed sense of hope and belief in goodness of life (Davidson et al., 2001). It has also been found to be important in rediscovering a persons' areas of strength and competence (Davidson, 2003).

The term self-care is used in this study to mean the tasks and skills to attend to personal care such as bathing, personal hygiene, hair and nail care, and dressing. It also includes the domestic tasks and skills that contribute to personal care, such as shopping, cooking, meal planning, laundry, clothes care, cleaning, tidying and maintenance of home, budgeting and using public transport.

The organization of occupations into a daily routine is an important dimension of occupational performance. A routine has been defined as

*“an established and predictable sequence of tasks.”* (Creek, 2010, p.108)

Developing a daily routine of occupations enables a person to spend their time in a personally meaningful way as well as supporting the person to meet the demands of their environment. Having a routine relieves the person from constantly having to make decisions about what to do and when to do it (Ludwig, 1998). For example, having a weekly routine of domestic chores ensures the person always has clean clothes and can locate items in the home when needed. Having an illness, a relapse of mental illness or an admission to hospital can disrupt a persons' routine.

### **1.3 Psychosis**

Psychosis is a term used to describe a set of symptoms that include delusions, hallucinations, hearing voices for example, and confused or disturbed thoughts. Psychosis is a general term for a class of disorders including schizophrenia, bipolar disorder and schizoaffective disorder. It can also occur as a symptom of other illnesses, for example, people who abuse drugs and alcohol sometimes experience symptoms of psychosis. Psychosis can also occur as a side effect of some types of medication. The prevalence of schizophrenia and related disorders in England is estimated to be 5 per 1,000 (McCrone et al., 2008). It is estimated that 210,450 people currently have these conditions and by 2026 the figure is projected to be 243,931 (McCrone et al., 2008). Additionally, schizophrenia is recognised as the 14th highest cause of disability worldwide (World Health Organisation, 2008). Therefore a focus on reducing the disability caused by having a diagnosed psychotic disorder is an important component of health care.

The focus of this study is adults of working age with a psychotic disorder with a diagnosis of schizophrenia, or schizoaffective disorder. The onset of a psychotic disorder is typically during adolescence, an age when individuals are establishing their independence. Many adults with this disorder will therefore experience an interruption in learning of skills normally acquired during teenage years and early adulthood (American Psychiatric Association, 2000). It has been found that people with schizophrenia have significantly lower motor and process skills when performing activities of daily living, compared to adults with no mental health diagnosis (Girard et al., 1999). Reduction in these process skills, less daily routine and reduced motivation for occupation were found in an analysis of clinical assessments of occupational performance of people with a diagnosed psychotic disorder (Lee et al., 2011). Time use studies have shown that the predominant occupations of people with a diagnosed psychotic disorder were found to be sleeping, eating, caring for oneself, and performing quiet activities, such as sitting and watching people or objects (Bejerholm & Eklund 2004; Harvey et al. 2006; Shimitras, Fossey, & Harvey 2003).

In the UK, adults with a diagnosed mental health problem are one of the most socially excluded groups in society (Social Exclusion Unit 2008). This indicates reduced participation in leisure, educational and social occupations. The consequences of having difficulties with occupational performance for people with a diagnosed psychotic disorder are evident therefore for the individual and society.

### **1.4 Health Policy**

Recent government and health policies relating to mental health services have moved beyond solely focusing on symptom management to focusing on the occupations of the individual. One of the objectives recently set by the government is that more people with mental health problems will recover (Lambert, Harrison & Watson, 2007). The indicators of success in meeting the objective are a greater ability to manage their own lives, having stronger social



relationships, a greater sense of purpose and the skills needed for living and working, with improved chances in education. Additionally the objective outlines that more people with mental health problems will have better employment rates and a suitable and stable place to live. The objective places value on everyday living rather than pathology and symptoms. The objective also stresses each person's unique view on what has meaning and importance in his life alongside independent living skills. This indicates a need for interventions to support people with mental health problems to develop the skills needed to choose and to participate in occupations of meaning to them.

## **1.5 Return to living in the community post discharge**

People with a diagnosed psychotic disorder are the most common diagnostic group to be admitted to an acute mental health hospital and also to be re-admitted to hospital (Langdon et al., 2001). The time after hospital discharge is a pivotal transition for people with a mental illness (Kolehmainen, 2009). A study of assessed unmet need six weeks post-discharge from hospital identified unmet needs for 173 individuals in relation day time activities (26%), food (12%), looking after their home (5%), and self-care (11%) (Simons & Petch, 2002).

Current legislation for the provision of post discharge care for people with mental health problems consists of Section 117 of the 1983 Mental Health Act (HMSO, 1983). Section 117 addresses the after-care requirements for people who have been in hospital on a treatment section (Section 3), or on Sections 37, 47 or 48. Aftercare itself is not defined in the Mental Health Act but the Code of Practice for the Act says:

*"After-care is a vital component in patients' overall treatment and care. As well as meeting their immediate needs for health and social care, after-care should aim to support them in regaining or enhancing their skills, or learning new skills, in order to cope with life outside hospital"*

(Department of Health, 2008a, p.250)

Currently after-care requirements are for service users on the Care Programme Approach (Department of Health, 2006). The Care Programme Approach (CPA) was introduced in 1990 to provide a framework for effective mental health care for people with severe mental health problems. Its four main elements are: systematic assessment of the health and social needs of people accepted into specialist mental health services; the appointment of a key worker (care co-ordinator) to keep in close touch with the service user, and to monitor and co-ordinate care; the formation of a care plan which identifies the health and social care required; regular review and, agreed changes to the care plan.

The after-care provision within CPA consists of one face-to-face follow up visit by a mental health professional within seven days of discharge. This requirement came as a result of the implementation of the National Suicide Prevention Strategy For England (Department of Health,

2002). The follow-up face to face meeting is aimed at assessing the person's mental state and ensuring they are taking their prescribed medication. With the exception of this mandate, currently there is no clear guidance, from the Department of Health regarding what clinical service a person with a diagnosed psychotic disorder can expect following discharge from hospital.

Studies of interventions for people with mental health problems following discharge from hospital have focused on improving continuity of psychiatric care. A study using a brief critical time intervention for three months following discharge found that it was helpful in promoting continuity of care post discharge (Dixon et al., 2009). The intervention consisted of nine possible target areas including life skills training, involving supporting the patient to improve his or her adaptive functioning in various life skills areas. The primary outcome for this study was service utility, in addition to measuring engagement with community services and use of inpatient services. A study of needs-oriented discharge planning for patients with high use of inpatient services showed no effect on number and duration of inpatient treatment (Puschner et al., 2011). The intervention consisted of two sessions with the service user and a member of the research team. The first session was pre-discharge and consisted of a needs assessment, structured discussion of need, and completion of a discharge plan. The second session was held three months post discharge and consisted of a second needs assessment and a structured discussion regarding implementation of the discharge plan. The study acknowledges that the intervention would benefit from incorporating support to enable the service users to make the transition from hospital to taking responsibility for their lives in the community post discharge.

#### **1.5.1 Occupational performance following discharge from hospital**

Resuming ordinary life following admission to hospital can be a challenge for people with a psychotic disorder (Roy et al., 2009). It has been found that, at the point of discharge, patients with multiple admissions are more likely to have difficulty with hygiene, have fewer social contacts and to be engaged in fewer leisure time activities than patients without multiple admissions (Owen et al., 1997). This could indicate the effect of the disruption of life caused by multiple admissions can have on occupational performance, or it could also indicate a decrease of occupational performance due to ongoing unstable mental health.

Following discharge from hospital service users often find themselves living in a new neighbourhood. This affects occupational performance by removing familiar community resources and often increasing geographical distance to friends and family. This can lead to occupational deprivation, which means preclusion from occupational performance due to external factors (Whiteford, 2000).

## **1.6 Importance of this study**

This study aimed to generate new knowledge regarding occupational performance for people with a diagnosed psychotic disorder following discharge from hospital. The rationale for focusing on the time following discharge is to ensure interventions to improve occupational performance are delivered in a timely manner, to maximise recovery and improve functional status post discharge to prevent long term disability. Current arrangements regarding support from health services following discharge from hospital focus on medication and monitoring of mental health. Many service users may therefore have to return home to deal with the ongoing problems with daily living tasks following discharge from hospital.

No studies were found investigating problems of occupational performance for people with a diagnosed psychotic disorder following discharge from hospital. Additionally, no service user accounts describing the difficulties with occupational performance experienced discharge from hospital have been found. The focus groups held in stage one of this study generated new knowledge regarding problems with occupational performance for people with a diagnosed psychotic illness, following discharge from hospital. A new intervention to address these problems with occupational performance was developed using best evidence available and applying appropriate theory to its development. A pilot study of the intervention was completed which will inform a full evaluation of the intervention in a randomised controlled trial in the future.

This study adds to the body of knowledge regarding interventions to prevent long term disability and support recovery following a hospital admission. Currently no interventions have been found to specifically improve occupational performance following discharge from hospital. This study forms a distinct contribution to the knowledge regarding people with a diagnosed psychotic disorder by piloting an evidence based intervention to improve occupational performance following discharge from hospital. Interventions to improve specific occupational performance problems related to being recently discharge from hospital can support reorganization of occupational performance tasks and skills in a timely manner. This can prevent long term disability.

## **1.7 Aims of the study**

The aims of this study were to develop and evaluate the preliminary effectiveness of an intervention to improve occupational performance for people with a diagnosed psychotic disorder living in the community following discharge from hospital. The study consisted of two stages:

Stage 1: Development of the intervention

Stage 2: Pilot study of the developed intervention

## 1.8 Structure of the thesis

The Medical Research Council (MRC) Framework for Developing and Evaluating Complex Interventions (Medical Research Council, 2008) was used as a research framework for this study. The framework outlines guidance on the development, evaluation and implementation of complex interventions to improve health. It is intended to help researchers to choose and implement appropriate methods, given the current state of what is known about the area. The framework has a focus on adequate development of an intervention and adequate piloting work prior to full evaluation of the intervention. The framework consists of four stages, development, feasibility/piloting, evaluation and implementation. The stages interact with each other but are not linear or cyclical (Medical Research Council, 2008).

The MRC describes complex interventions as having the following characteristics:

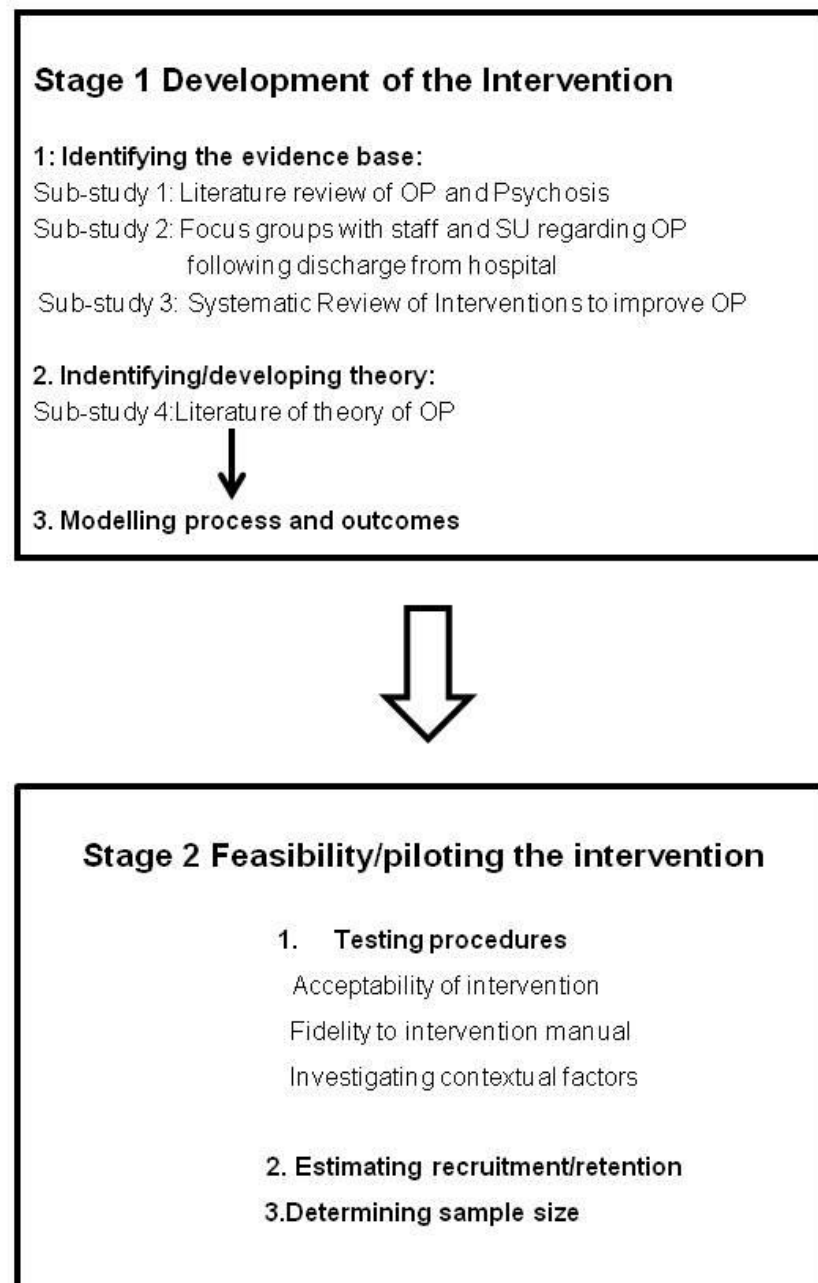
- Built up from a number of components, which may act both independently and inter-dependently
- A number of behaviours, some of which are difficult, required by those delivering or receiving the intervention
- A number of outcomes and variability of outcomes.
- A degree of flexibility or tailoring of the intervention is required

(Medical Research Council, 2008)

Interventions aimed at improving occupational performance are complex as components involved in occupational performance interact to influence occupational performance. The range of possible outcomes is unique to each person, as occupational performance preferences are individual. It is also important that the intervention can be tailored to each individual.

The thesis begins by examining the background and context of the study and goes on to follow the steps involved in developing the intervention as outlined in the MRC Framework for developing and evaluating complex interventions 2008. Figure 1.1 outlines the study as structured by the MRC framework.

**Figure 1.1 Study design following the MRC framework for developing and evaluating complex interventions**



The thesis outlines the tasks involved in developing the intervention in Chapters 3-6. One of the tasks was to define the problem regarding occupational performance for people with psychotic disorders following discharge from hospital. Chapter 2 consists of a literature review of occupational performance for people with a diagnosed psychotic disorder.

The MRC framework also suggests that, in developing the intervention, expert opinion is gained to supplement the theory base. Therefore, the results of a focus group with service users regarding their views of occupational performance following discharge from hospital are also described in Chapter 3. Currently Occupational Therapists (OTs) and Support Time and Recovery (STR) Workers deliver interventions to improve occupational performance for people with a psychotic disorder. Therefore the results of a focus group consisting of OTs and an STR worker are also outlined in Chapter 3 and informed the development of the intervention.

Another element of developing a complex intervention is to identify the existing evidence base that can support the intervention. Chapter 4 consists of a systematic review regarding interventions to improve occupational performance for people with psychotic disorders to identify existing interventions that may exist regarding improving occupational performance following discharge from hospital. The review was also carried out to identify interventions that may inform the development of a new intervention. The MRC framework recommends a clear theoretical base is defined on which the intervention is based, to this end, a literature review regarding the theories and models relating to occupational performance are described in Chapter 5.

The MRC framework outlines the above process to gather data from a variety of sources to develop an intervention. Little guidance is documented, however, within the framework regarding how to collate this information to form an intervention. An outcome measure will be tested as part of the pilot study in stage two of the study. Chapter 6 outlines the process regarding the development of the intervention and the method used to develop a model of action of the intervention as well as the manualisation of intervention. In Chapter 7, consideration is given to suitable outcome measurement tools for use in evaluating the intervention.

The MRC framework outlines the development-evaluation-implementation process, where by once the intervention has been developed, the next stage is assessing feasibility and piloting of the intervention. The methodology used during the second stage of the study to pilot the intervention and outcome measure, is described in Chapter 8, with Chapter 9 presenting the results. A discussion of the methods used and results of pilot study are discussed in Chapter 10.

The results of this study aim to add to the body of knowledge regarding what is known about occupational performance of people with a diagnosed psychotic disorder, following discharge from hospital. The results of the pilot study will also add to the body of knowledge regarding interventions following discharge from hospital, and can inform future intervention studies.

# Chapter 2 Occupational Performance and Psychosis

## 2.1 Introduction

This is the first of four chapters which inform the development of an intervention to improve occupational performance for adults with a diagnosed psychotic disorder, following discharge from hospital. The development of the intervention follows the MRC framework (Medical Research Council, 2008). The framework emphasises the importance of thoroughly developing an intervention, to ensure a worthwhile effect, prior to evaluating it. To thoroughly develop an intervention, the complexities of the clinical problem need to be understood. Additionally the relationships between these complexities need to be clearly recognised. This will enable the intervention to target the identified problematic aspects of occupational performance and have the greatest impact on improvement (Campbell et al., 2007). This chapter consists of sub-study one, a review of the literature regarding occupational performance of leisure and self-care in people with a diagnosed psychotic disorder including following discharge from hospital.

## 2.2 Method

The aims of this chapter are to outline the occupational status of people with a diagnosed psychotic disorder and what is known regarding the problems of occupational performance of people with a diagnosed psychotic disorder. Studies with over 70% of participants with a diagnosed psychotic disorder will be included. These aims were met by identifying published research studies and synthesising the results. This will enable the development of an intervention to act on the specific problems identified. Models relating to occupational performance for people with a diagnosed psychotic disorder that will also influence the intervention are outlined in Chapter 5.

The literature was searched in May 2010 using CINAHL, Embase, PsycINFO and Medline databases. The search terms used are presented in Table 2.1.

**Table 2.1 Search terms used in the review**

Occupation* AND functioning		Psychosis
Impairment	AND	Psychotic illness/
adaptation		Schizophrenia
engagement		Schizoaffective
performance		Severe and enduring mental
Participation in daily life		health
Function* AND performance		
recovery		
status		
outcomes		
skills		
Activities of daily living		
Independent living skills		
Psychosocial functioning		
Community living skills		
Self-care		
Leisure		

Abstracts and then full papers of identified studies were reviewed. Inclusion criteria were a focus on occupational performance of adults with a diagnosed psychotic disorder or where at least 70% of the participants had a diagnosed psychotic disorder. A quality assessment was carried out on each qualitative study included using RATS (Relevance, Appropriateness, Transparency, Soundness) qualitative research review guidelines (Clark, 2003). The RATS scale comprises 25 questions regarding the relevance of the study question, appropriateness of qualitative method, transparency of procedures, and the soundness of interpretive approach used. For each of the 25 questions the researcher rated each study by giving a score of one for each yes and 0 for each no answer. Studies with a score of 25 therefore indicate high quality and studies with a score of 0 indicate poor quality. The quality assessment tool for quantitative studies developed by Effective Public Health Practice Project was used to rate the quality of included quantitative studies (Effective Public Health Practice Project, 2009).

## 2.3 Results

Twenty three papers were located in the review. Ten of the studies used qualitative methods and 13 used quantitative methods to investigate aspects of occupational performance. They consisted of self-reports of occupational performance obtained from semi structured interviews and one study used photovoice and observed findings regarding occupational performance for people with a diagnosed psychotic disorder. The observed findings regarding occupational performance were obtained from multiple linear regression analyses, epidemiological surveys and results of observer rated outcome batteries.

A summary of the studies included in this review can be found in Table 2.2.

**Table 2.2 Summary of studies included in literature review**

Study	Sample	Method	Aims
Andonian (2010)	Five participants, three with schizophrenia in USA	action research Photovoice	How people with mental health problems describe their access to and community participation
Aubin, Hachey & Mercier (1999)	45 adults with severe and persistent schizophrenia in Canada	Semi structured interviews	To explore the relationship between meaning of activities and subjective quality of life for people
Aubin, Stip, Gelinas, Rainville & Chapparo (2009)	82 participants with schizophrenia in Canada	Observation and self-rated questionnaires	To describe the limitations in information-processing skills observed performing daily tasks.
Bejerholm (2010)	72 people with schizophrenia in Sweden	Descriptive study using self- rated questionnaires	To investigate the relationship between satisfaction and status of occupational engagement, and with socio-demographic factors.



<b>Study</b>	<b>Sample</b>	<b>Method</b>	<b>Aims</b>
Bejerholm & Eklund (2004)	Ten people with schizophrenia in Sweden	24 hour time-use diary	To describe time use and to understand their daily occupations, social and geographical environments, and reflections of their occupational performance.
Bejerholm & Eklund (2006)	20 people with schizophrenia in Sweden	Time-use diaries and semi structured interview	To describe engagement in occupations
Chugg & Craik (2002)	Eight people with schizophrenia in UK	Semi-structured interviews	To identify factors influencing occupational engagement in the community.
Cook & Chambers (2009)	24 people with a diagnosed psychotic disorder in UK	Semi-structured interviews	To establish what helps and hinders people with psychotic conditions to do what they want
Craik & Pieris (2006)	10 participants of assertive outreach team in UK	Semi-structured interviews	To establish the meaning and value of leisure for people with enduring mental health problems living in the community
Emerson, Cook, Polatakjo & Segal, (1998)	Nine participants with a diagnosed psychotic disorder in Canada	Semi-structured interviews	To describe enjoyment experiences of people with schizophrenia
Eklund & Leufstadius (2007)	103 participants with persistent mental illness, 60% with a psychotic disorder, in Sweden	Interview-based assessment of satisfaction with daily occupations	To identify relationships between occupational factors and health and well-being among individuals with a persistent mental illness.
Evert, Harvey, Trauer, Herman (2003)	908 participants with psychosis in Australia	Epidemiological survey and semi structured interviews	To describe the social networks of people with psychosis and to investigate relationships between social networks and occupational functioning, taking account of illness course.
Girard, Fisher, Short & Duran (1999)	129 participants, 43 with schizophrenia, in USA	Observer rated measure of motor and process skills regarding activities of daily living	To compare the occupational performance of non-disabled people, people with depression and people with schizophrenia
Harvey, Fossey, Jackson & Shimatras (2006)	192 people with schizophrenia in UK	24 hour time-use diary	To identify illness-related and socio-demographic predictors of the participant of people with schizophrenia.
Hitch (2009)	Ten adults, (five staff plus five service users, three with diagnosed psychotic disorder) in UK	Semi-structured interviews.	To describe the experience and meaning of engagement for staff and clients of assertive outreach teams.

Study	Sample	Method	Aims
Hofer, Baumgartner, Bodner, Edlinger, Hummer, Kemmler, Rettenbacher, & Fleischhacker (2005)	60 adults with schizophrenia, in Austria	Cross-sectional study	To investigate the relationships between quality of life, needs and psychosocial functioning
Leufstadius, Erlandsson, Björkman & Eklund (2008)	102 adults, 59 with a diagnosed psychotic disorder in Sweden	24 hour time-use diaries.	To investigate how people with persistent mental illness, who have different types of daily structure, experience and describe the meaningfulness of their daily occupations.
Mausbach, Depp, Cardenas, Jeste & Patterson (2008)	240 middle-aged and older adults with a diagnosed psychotic disorder, in USA.	Assessment battery using questionnaire	To determine whether patients residing in residential care engaged in fewer community responsibilities relative to those residing in the community.
Nagle, Cook & Polatajko, (2002)	Eight adults with a severe and persistent diagnosed psychotic disorder in Canada	Semi - structured interviews	To understand the occupational experience of people with severe and persistent mental illness
Owen, Rutherford, Jones, Tennant, & Smallman (1997)	128 participants with mental health problems in Australia	Assessment battery using questionnaires	To examine the patient characteristics at discharge associated with likelihood of rehospitalisation.
Roy, Rousseau, Fortier & Mottard (2009)	19 participants with first-episode psychosis in Canada	Case study using Semi-structured interviews	To explore the perception of people with first-episode psychosis regarding their community functioning
Shimatras, Fossey & Harvey (2003)	229 adults with schizophrenia in England	Epidemiological survey semi structured interviews using a time budget to record daily time use.	To examine the time use of adults with schizophrenia within an urban population
Wittorf, Wiedemann, Buchkremer, & Klingberg (2007)	96 adults with mental health problem, 66.6% with a diagnosed psychotic disorder in Germany	Multiple linear regression analyses of outcome data regarding global assessment of Functioning	To identify predictors of functional outcome in schizophrenia.

Table 2.3 presents the quality assessment ratings for each of the included studies, using RATS for qualitative studies and the quality assessment tool for quantitative studies developed by Effective Public Health Practice Project for the studies using quantitative analysis.

**Table 2.3 Quality assessment ratings of included studies**

Study	Rating	Weak components
<b>Qualitative studies</b>		
Andonian (2010)	24/25	Ethical approval not cited
Bejerholm & Eklund (2006)	25/25	
Chugg & Craik (2002)	21/25	No details of who chose not to participate and why  Method of data collection not outlined and no examples given  Study group and setting not described  End of data collection not justified or described
Cook & Chambers (2009)	25/25	
Craik & Pieris (2006)	17/25	No details of how recruitment was conducted and by whom  No details of who chose not to participate and why  Study group and setting not described  End of data collection not justified or described  The researcher does not critically examine the ethics of occupying dual role of clinician and researcher  The researcher does not critically examine their own influence on research  Analytic approach not described in depth or justified  Trustworthiness/reliability of the data and interpretations not checked  Strengths and limitations not explicitly described and discussed
Emerson, Cook, Polatajko & Segal, (1998)	24/25	Ethical approval not cited
Hitch (2009)	21/25	No details of who chose not to participate and why  End of data collection not justified or described  The researcher does not critically examine the ethics of occupying dual role of clinician and researcher  The researcher does not critically examine their own influence on research
Leufstadius, Erlandsson, Björkman & Eklund (2008)	25/25	
Nagle, Cook & Polatajko, (2002)	11/25	Sampling strategy not described  No details of how recruitment was conducted and by whom

Roy, Rousseau, Fortier & Mottard (2009)	23/25	Method described as multiple case studies and not analysed as case studies. Analytic approach not described in depth and justified.
Quantitative studies		
Aubin, Hachey & Mercier (1999)	Strong	
Aubin, Stip, G��linas, Rainville & Chapparo, 2009	Moderate	Data collection methods not shown to be valid or reliable
Bejerholm, 2010	Moderate	There were important differences in participants in that two thirds of the sample were men
Bejerholm and Eklund, 2004	Moderate	There were important difference in participants in that eight of the ten participants were men
Eklund and Leufstadius,, 2007	Strong	
Evert, Harvey, Trauer and Herrman, 2003	Weak	Can't tell if there were important differences in participants
Girard, Fisher, Short and Duran, 1999	Strong	
Harvey, Fossey, Jackson, and Shimitras, 2006	Moderate	Data collection methods not shown to be valid or reliable
Hofer, Baumgartner, Bodner, Edlinger, Hummer, Kemmler, Rottenbacher and Fleischhacker, 2005	Strong	
Mausbach, Depp, Cardenas, Jeste, and Paterson, 2008	Strong	
Owen, Rutherford, Jones, Tennant and Smallman, 1997	Strong	
Shimatras, Fossey and Harvey, 2003	Strong	
Wittorf, Wiedemann, Buchkremer and Kilingberg, 2008	Strong	

As can be seen from Table 2.3, the quality ratings of qualitative studies ranged from 11 to a maximum score of 25, and the quality assessment of the quantitative studies varied from weak to strong, with eight of the 12 studies receiving a rating of strong. All studies were included in the review. On reviewing the studies, they were grouped together according to the emerging foci of the studies.

### 2.3.1 Researcher-rated studies of occupational performance

#### *Cognitive functioning*

Both longitudinal and cross-sectional studies suggest that cognitive functions, particularly memory, limit functional outcomes (Hofer et al., 2005). Additionally, a study of people with schizophrenia found that problematic information-processing skills were observed during daily task performance (Aubin et al., 2009). Participants with higher levels of information-processing skills were more independent in their living skills and more successful in attaining residential

independence compared with participants with more deficits in information processing skills. No differences in severity of symptoms were found between these groups.

#### *Gender differences*

Gender differences have been found regarding the course and prognosis of schizophrenia relating to occupational performance. Women with schizophrenia tend to have a higher age of onset of the disorder than men, and a better prognosis for social and occupational achievements after onset (American Psychiatric Association, 2000). It has also been found that men present with poorer self-care than women and that women have more social contacts than men (Evert et al., 2003). This finding regarding gender differences for self-care was similarly found in another study where, while both men and women spent time at home, women spent more of this time engaging in a daily routine of self-care in the morning, whereas men were mostly disengaged from meaningful occupations at home (Bejerholm & Eklund, 2006).

#### *Developmental impact*

People who develop schizophrenia often fail to accomplish age-related developmental occupations in work, self-maintenance and play (American Psychiatric Association, 2000). This may be a result of skill development being disrupted at onset of psychosis, with men on average having achieved a lower level of skill development at onset due to earlier onset of illness than women, thus impacting on their social and occupational attainments. Therefore interventions to improve occupational performance for people with a diagnosed psychotic disorder will need to take into account the need for skill development regarding self-care and leisure.

#### *Motor and process skills*

Differences in occupational performance have been found between people without a diagnosed mental health problem and people with a diagnosis of schizophrenia (Girard et al., 1999). In this study, the Assessment of Motor and Process Skills (AMPS) was used to measure participants' motor and process abilities during performance of activities of daily living. Participants with schizophrenia showed significantly lower levels of motor and process skills compared to participants without a psychiatric diagnosis. Motor skills consist of physical actions used during task performance to move objects or self. The deficits in motor skills found in participants with schizophrenia may be as a result of side effects of medication the authors of this study proposed, however this has not been studied. Process skills consist of the component actions of task performance, including the ability to organize, use knowledge and adapt the actions of task performance.

#### *Negative symptoms*

Negative symptoms of schizophrenia have been described as the person presenting as withdrawn, emotionless, flat and apathetic. A study of 96 people with schizophrenia, identifying predictors of community outcome a year after discharge from hospital found that the presence

of negative symptoms showed highest prediction of problems with social and leisure functioning (Wittorf et al., 2007). However, a study by Harvey and colleagues found that negative symptoms were not predictive of participation in occupations (Harvey et al., 2006).

A study of mental health service users found that those who were readmitted to hospital had been found at discharge to have more difficulties with hygiene and fewer leisure pursuits (Owen et al., 1997). No studies of problems of occupational performance following discharge from an adult acute mental health ward were found.

#### *Social networks and occupational performance*

A study of the relationship between social networks and self-care found that dysfunction in self-care was significantly associated with socially isolated participants of the study (Evert et al., 2003). The study was a two-phased epidemiological study using questionnaires and semi structured interviews to gather data relating to functioning and social networks. Additionally male gender was strongly associated with poorer self-care and female participants significantly associated with a greater likelihood of having friends. However, despite the study finding a strong association between social integration and functioning, the nature of the association has not been established.

#### *Quality of life and occupational performance*

A study of people with persistent mental illness, 80% of whom had a diagnosed psychotic disorder, were assessed regarding time use, satisfaction with occupations, and experienced value of occupation (Eklund & Leufstadius, 2007). The study found a significant relationship between both value and satisfaction with daily occupations and quality of life. This confirms the finding of a previous study which found that people with a mental illness perceive a better quality of life when they felt competent and satisfied in their ability to carry out daily tasks (Aubin, Hachey & Mercier, 1999).

#### *Community engagement and housing status*

A study of participants with a diagnosed psychotic disorder examined the relationship between community engagement and housing status, that is, residential care facilities or community dwelling (Mausbach et al., 2008). The study also examined the relationship between functional capacity and community engagement. The study found that participants living in the community participated in significantly more community opportunities than those in residential care facilities. Both groups however, had similar level of functioning and demographic characteristics. The reason for the association between level of community participation and housing status has not been established. A study of time-use of people with a diagnosed psychotic disorder from North London found that there was no difference between housing status and level of participation in active leisure and social occupations (Harvey et al., 2006). However, living alone was found to be significantly associated with passive leisure.

Five studies utilising time-use methods with people with a psychotic disorder were found (Bejerholm & Eklund, 2004; Bejerholm & Eklund, 2006; Harvey et al., 2006; Leufstadius et al., 2008; Shimitras, Fossey & Harvey, 2003). Three of these studies took place in a city in Sweden and two from England. An epidemiological study of adults with schizophrenia identified that time use amongst people with schizophrenia in a north London area consisted predominantly of sleeping, personal care, and passive leisure, for example watching television or listening to music (Shimitras et al., 2003).

Related results were found in a study of occupational balance in people with schizophrenia (Bejerholm, 2010), which identified that more than half the participants were under-occupied. Being under-occupied is defined by Bejerholm (2010), as a lack of transaction between the person and their environment and having few occupational opportunities.

#### *Occupational performance and its relationship with age*

The study by Harvey and colleagues, also examined participation in passive and active leisure and social participation. The study found that younger participants were more likely to participate in social occupations than older people. The presence of symptoms was not predictive of participation in any of the occupations. The results of this study could indicate that there are more barriers to participation in social occupations for older adults.

### **2.3.2 Self-report studies of occupational performance**

Studies in this area consist of results of individual interviews and focus groups with people with a diagnosed psychotic disorder. No studies were found specifically related to occupational performance following discharge from hospital.

#### *Disruption by illness of occupational goals and aspirations*

A study of occupational choices found that the onset of illness forced participants to abandon their valued occupations and aspirations (Nagle et al., 2002). The participants also chose less ambitious occupational goals following onset of illness.

#### *Leisure*

In a study exploring leisure occupations amongst service users of a community assertive outreach team, some of the participants identified that they felt anxious about participating in leisure (Craik & Pieris, 2006). This often prevented them from taking part in leisure activities on a regular basis. The participants also identified that lack of social contacts prevented them participating leisure occupations, as they did not want to be on their own. Three studies identified that the service users preferred to and engaged more in leisure when events were organised for them (Chugg & Craik, 2002; Cook & Chambers, 2009; Hitch, 2009). The participant of one study outlined how he accessed more leisure when he moved to

accommodation where staff organised cinema and art groups (Chugg & Craik, 2002). In a study of ten participants, five of which were staff and five were service users of an assertive outreach team, the service user participants identified the need to provide structure for engagement in occupations (Hitch, 2009). Restricted financial means limited participation in leisure occupations also (Nagle et al., 2002). The studies of leisure occupations have found that service users have identified that anxiety, social factors and level of support impact on their performance of leisure occupations.

#### *Self-Care*

One study was found that reported problems regarding domestic activities of daily living. The participants in the study by Andonian, found shopping and meal preparation a challenge, in addition to managing their home environment (Andonian, 2010). Two studies were found that describe problems with personal activities of daily living. Two of the participants in the study by Andonian identified that difficulties with personal and domestic activities of daily living were barriers to participating in the community as they were often wearing dirty clothes and had not showered (Andonian, 2010). This finding is further confirmed by the study by Chugg and Craik where a participant identified that having a shower every day helped her/him to continue to do things on a regular basis outside the home (Chugg & Craik, 2002). These findings further confirm the relationship between problems with self-care and reduced social contacts (Evert et al., 2003).

#### *Routine*

Several studies regarding occupational performance for people with a diagnosed psychotic disorder have examined the meaning of having a daily routine of occupations (Bejerholm, Hansson & Eklund, 2006; Chugg & Craik, 2002). A study of people with schizophrenia living in London found that for two participants, having a daily routine helped them to do other things that they wanted to do (Chugg & Craik, 2002). However, for the majority of participants, a lack of a weekend and evening routine resulted in them being isolated at home. One female participant in the study, by contrast, avoided routines as a means of reducing pressure on herself. One study found the female participants had a daily routine of household occupations, whereas the male participants had no such routine at home (Bejerholm & Eklund, 2006).

#### *Meaning of occupation*

The literature regarding occupation has identified that every occupation has some meaning to the individual (Hammell, 2009). The literature also proposes that having a sense of meaning is inextricably bound with our identity and that meaningfulness enhances a person's sense of well-being (Ikiugu, 2005). A study investigating the meaningfulness of daily occupations for people with persistent mental illness, 60% of whom had a diagnosis of schizophrenia, found a number of occupations were meaningful (Leufstadius et al., 2008). The five main themes relating to meaningfulness were occupations that connected them with others and the world around them,



enjoyment and fun in life, having a sense of achievement, having a routine, and taking care of oneself. Enjoyment has been found to be associated with the experience of accomplishment and a sense of curiosity (Emerson et al., 1998). The participants in the study by Chugg and Craik also identified that pleasure was an important factor influencing occupational performance. They also identified that engagement in occupational performance enabled them to reach their potential and increase the quality of their life. A further study examining the meaning of daily activities for 45 people with schizophrenia, (Aubin et al., 1999) found that the participants identified sleeping as being meaningful to them, in that it was ranked highly for perceived pleasure and importance. Paid employment, however, was ranked as the most important overall. However, it has also been found that people with a diagnosed psychotic disorder chose a level of engagement in occupations that they feel supports them to remain well (Nagle et al., 2002). They chose their occupations to maintain social connections, health and occupational needs.

### **2.3.3 Self-reported factors that hinder occupation performance**

People with a diagnosed psychotic disorder have described the factors that hinder them doing what they wanted in their daily lives in several self-report studies. Internal and external factors were identified. One of the internal factors identified in a study of eight participants is lack of self efficacy (Chugg & Craik, 2002). A lack of motivation and energy, sleep difficulties, anxieties and lack of confidence, substance misuse and gambling were also identified as internal factors hindering occupational performance (Cook, 2009). Additionally, physical health problems, fear of exacerbating mental health difficulties, traumatic events from the past, and problems coming to terms with mental health difficulties were also identified (Cook, 2009; Roy et al., 2009). A study exploring the experiences of community urban living, identified two internal factors limiting participation in community occupations; risks of being stigmatised and medication side effects (Andonian, 2010). The external factors the service users identified were poor living conditions and difficulties with neighbours, lack of leisure and work opportunities, seasonal difficulties, demands of caring for others, family disconnections and misunderstandings, poor service delivery and unsatisfactory relationships with mental health workers (Cook, 2009).

### **2.3.4 Environmental factors**

As can be seen from the definition in Section 1.3, occupational performance occurs in interaction with the environment. Therefore the environment can influence occupational performance and is an important aspect to examine in order to understand the occupational performance of people with a diagnosed psychotic disorder.

#### *Physical Environment*

A study of people with schizophrenia found that they spent most of their time at home alone with no interaction with their environment (Bejerholm & Eklund, 2004). The study also found that little time was spent on playful activities with other people, indicating reduced interactions within

social environments. The participants' also reported spending little time in their local neighbourhood environment. The study does not investigate causes for this lack of interaction with their environment, but the author suggests that lack of adaptive capacity may inhibit interaction with their environment. The study identifies the need for interventions to reshape the environment in order to promote opportunities for occupational performance.

Despite this literature review not focusing specifically on first-episode psychosis, some of the factors relating to first episode psychosis are similar to being discharged from hospital to a new address. A study using semi-structured interviews with young adults with recent-onset psychosis found that the young people experienced residential instability as they were housed in an unfamiliar neighbourhood following onset of illness, which led to them feeling socially isolated (Roy et al., 2009). The impact of change of social and physical environment resulted in them being isolated from their previous location for hobbies and socialising with friends. Additionally, they were unfamiliar with local community resources. The study indicated that the participants' home environments impacted on their level of functioning as the environment was not always satisfying to the individual. The study recommends that interventions to increase residential stability and to adapt the home to the persons strengths and difficulties. It also recommends interventions to address the impact of neighbourhood environment on the person's functioning.

A study of 24 people with psychosis also identified poor living conditions and relationships with neighbours as factors affecting their ability to do what they wanted with their lives (Cook & Chambers, 2009), indicating the significance of the person's social and physical environment regarding occupational performance.

### *Social Environment*

The social environment was also identified as an important factor by participants in the study by Chugg and Craik, in that having someone with them supported successful completion of every day occupations (Chugg & Craik, 2002). Participants in the study by Hitch also identified that the interpersonal relationships with others involved in the occupation is important, and they valued working with others towards a shared goal. A study of enjoyment experiences for people with schizophrenia found that feeling socially connected during community occupations was important (Emerson et al., 1998). This finding links with that of a study using photovoice as action research methodology to identify what affects community participation for people with mental health problems (Andonian, 2010). The five participants of this study, three of which had schizophrenia, identified the importance of friendships, and support of family, friends and service providers, and the ability to use public transport in participating in community occupations including leisure. This further indicates the importance of the social environment for the person with a diagnosed psychotic disorder.

## **2.4 Summary and discussion**

This chapter outlined findings of studies investigating factors impacting occupational performance and studies describing daily occupational performance for people with a diagnosed psychotic disorder. The findings of this review add to the body of knowledge regarding what is known about occupational performance for people with a diagnosed psychotic disorder and can inform areas of assessment and interventions for this group of people.

The review identified that people with a diagnosed psychotic disorder are under occupied and spend the majority of their time participating in passive leisure and sleeping. Despite being under-occupied several studies described how people with a diagnosed psychotic disorder find value and personal meaning in occupations that connect them to others, provide fun, enjoyment and a sense of achievement. Problems with domestic and personal activities of daily living (ADLs) have been identified, in addition to difficulties using leisure facilities. Barriers to OP in the community have been identified as problems with domestic and personal ADLs, and a lack of a routine. Internal and external factors affecting occupational performance have been identified.

A significant external barrier to OP was found to be the persons' physical and social environment within their neighbourhood and local community. Within the general population, a persons' local environment has been identified as impacting on mental health and well-being (Cooke et al., 2011). Therefore improvements to the local environment can have both benefits for OP and mental health for people with a diagnosed psychotic disorder. This indicates that interventions to improve OP of people with a diagnosed psychotic disorder should include community level interventions, aiming to improve the local resources and social environment for the whole community.

An important internal barrier to occupational performance identified in this review is fear of exacerbating mental health difficulties (Cook, 2009; Roy et al., 2009). This links with the finding that people with a diagnosed psychotic disorder choose a level of engagement in occupations that they feel supports them to remain well (Nagle et al., 2002). People with a diagnosed psychotic disorder may be under-occupied because of their fear of exacerbating symptoms of mental illness. Providing support to enable people to increase their performance of occupations whilst enabling them to understand their occupational performance may enable them to balance the need for meaningful occupations with remaining well.

The review indicates two gaps in the knowledge regarding OP of people with a diagnosed psychotic disorder. Ability to perform domestic ADLs was documented in only two studies and therefore warrants further investigation. No studies were found regarding OP following discharge from hospital. An epidemiological study regarding patterns of occupational performance post discharge from hospital and at three and six months post discharge would

enable clinicians to identify the progress of changes in occupational performance and their context. This would support service development and intervention design for this stage of the clinical pathway.

## **2.5 Implications for interventions to improve Occupational Performance**

The range of factors impacting on OP identified in the studies demonstrates the complexity of problems of occupational performance. The findings of this review have implications for interventions to improve occupational performance for people with a diagnosed psychotic disorder. Interventions will need to address possible skills deficits due to developmental impact of illness. Interventions will also need to take into account methods to improve process skills within each occupation carried out. Additionally an intervention will need to be sensitive to address gender specific problems with occupational performance and increasing participation in identified problematic occupations. To increase participation in leisure occupations in a sustained way, interventions to improve OP in this area will require consideration of the persons' planning skills and improving social contacts. Interventions to improve OP will need to consider the need to support the individual to overcome environmental factors hindering OP.

## **2.6 Implications for interventions to improve occupational performance following discharge from hospital**

No studies of OP following discharge from hospital were identified in this review. The results of the review, however, identified important factors to take into account in developing an intervention to improve occupational performance for people with a psychotic disorder following discharge from hospital. Two studies (Aubin et al., 2009; Harvey et al., 2006) found that the clinical symptoms of psychotic disorders were not predictive of problems of occupational performance. In inpatient settings discharge planning is focused on stability of mental state, therefore service users on discharge may have a reduction in clinical symptoms but problems with occupational performance may still be present. This reaffirms the need to provide an intervention on discharge specifically to improve OP. Table 2.3 summarises the results of the review and outlines the implications of the findings on the development of the intervention.

**Table 2.4 Summary of results of review and implications for the development of the intervention.**

<b>Findings</b>	<b>Implication for the intervention</b>
<b>cognitive function</b> memory and information processing skills limit functional outcomes	Assessment of OP skills to be included
<b>Gender difference</b> Women have better prognosis for social and occupational outcomes than men.  Women spend more time engaging in daily routine of self-care than men  Men disengaged from meaningful occupations at home.  Men present with poorer self-care than women  Lower level of skill development for men due to age of onset	These findings to be discussed during the training regarding implementing GLOW, to raise the clinicians' awareness of gender differences, whilst remaining client centred.
<b>Internal factors</b> Lack of: self efficacy, confidence motivation energy sleep difficulties  Physical health problems, substance misuse and gambling may impact on OP Risk of being stigmatised Medication side effects	Assessment of OP skills to be included
Lower levels of motor and process skills	Assessment of OP skills to be included
Negative symptoms may predict problems of social and leisure functioning	Findings to be discussed during the training regarding implementing GLOW, to raise the clinicians' awareness of affect on OP
<b>External factors identified by SU affecting OP</b> Poor service delivery Unsatisfactory relationships with Mental Health workers  Ability to use public transport facilitated community participation	Assessment of OP skills to be included
<b>Accommodation</b> Living in residential care may be associated with reduced participation in community opportunities compared to community residents with similar functional capacity  Living alone associated with passive leisure	Assessment of local environment to be included.
<b>Readmissions to hospital</b> Associated with difficulties with hygiene and fewer leisure pursuits	These findings to be discussed during the training regarding implementing GLOW, to raise the clinicians' awareness of the association between readmissions and OP

<b>Findings</b>	<b>Implication for the intervention</b>
<b>Quality of life</b> associated engagement in personally valued and satisfying occupations  Competence in occupational performance	Identification of valued occupations and service user led goal setting
<b>Meaningful Occupations</b> connect a person to others provide enjoyment and fun  A sense of achievement Enabling them to reach potential	Identification of meaning of occupations and service user led goal setting
<b>Age</b> Younger people participate more in social occupations than older people	These findings to be discussed during the training regarding implementing GLOW, to raise the clinicians' awareness of age in relation to OP
<b>Occupational status</b> Under-occupied Time spent sleeping, personal care and passive leisure.	Assessment of OP included in the intervention
<b>Leisure</b> Anxiety preventing participation Lack of social contacts and financial resources  are barriers to leisure Preference for organised structured activities	Assessment of OP included in the intervention  Intervention to take place in relevant community venue
<b>Domestic ADLs</b> Difficulties with shopping, meal preparation and managing home environment  Difficulty with laundry a barrier to community participation	Assessment of domestic ADLs included in the intervention
<b>Personal ADLs</b> Difficulties with self-care a barrier to community participation Daily showering supported regular community participation  Problems with self-care are associated with social isolation	Assessment of personal ADLs included in the intervention
<b>Routine</b> Daily routine supports being able to have more occupational choice  Lack of routine results in social isolation  Women more likely to have daily routine of household occupations than men.	Assessment of routine included in the intervention
<b>Environment</b> Reduced contact with social environment Friends, family and service providers helpful in participating in community occupations  A lack of adaptive capacity may prevent interaction with local environment	

<b>Findings</b>	<b>Implication for the intervention</b>
<b>Environment (continued)</b> Residential instability/unfamiliar neighbourhood home environment impacted on OP Poor living conditions and difficulties with neighbours impacted on OP	Assessment of home and neighbourhood environment

To fill the knowledge gap regarding OP following discharge from hospital, focus groups with service users and clinical staff, were held regarding their views of this topic, these are described in Chapter 3. The results of the focus groups provide a clear focus of the intervention and the results from this review contribute to the development of the intervention by ensuring a wider consideration of problems regarding OP. This will ensure the intervention designed to meet the OP needs following discharge also consider the long term goals of the service users.

The results of this chapter will be discussed in relation to the theory regarding occupational performance, and interventions identified in a systematic review to develop an intervention in Section 6.2.1.

Since completion of this literature review and development of the intervention, further literature has been published regarding occupational performance for people with a diagnosed psychotic disorder. This literature will be discussed in Section 10.4.

## Chapter 3 Occupational performance following discharge

### 3.1 Introduction to focus groups with staff and service users

The literature review in Chapter 2 regarding occupational performance for people with a diagnosed psychotic disorder found no studies regarding this problem specifically relating to the period following discharge from hospital. The MRC framework emphasises the importance of carrying out new research where little is known about the specific problem targeted by the intervention being developed. In this instance little is known about the specific problems of occupational performance post discharge, which the developed intervention will target. Therefore new research is needed to investigate these specific problems. To reduce this knowledge gap, qualitative methods were used to explore the experiences of people with a diagnosed psychotic disorder following discharge from hospital regarding their occupational performance in the areas of self-care and leisure. Qualitative methods were also used to explore the experiences of community mental health professionals in carrying out interventions to address everyday activities following discharge from hospital. This study presents sub-study two: focus groups with service users and staff, the study will contribute to the development of the intervention.

### 3.2 Methodology

#### 3.2.1 Choice of research design

A qualitative research design was chosen as the most suitable design for this sub-study, as not much is known about occupational performance following discharge for people with diagnosed psychotic disorder (Bowling, 2009). Focus groups were used to collect data which emerges through interaction between participants.

Focus group research involves organised discussion with a selected group of individuals to gain information about their views and experiences of a topic (Morgan, 1998). Focus groups have been used in this study to make use of group dynamics to stimulate discussion, gain insights and generate ideas in order to pursue the topic in greater depth. Interaction enables participants to ask questions of each other, as well as to re-evaluate and reconsider their own understandings of their specific experiences (Kitzinger, 1994). Focus groups are particularly suited to obtaining several perspectives from a group of individuals selected by researchers to discuss and comment on, from personal experience, the topic of the research (Bowling, 2009). Focus groups have been used for this study to enable each participant to prompt each other to recall information and describe detail that otherwise the individual participants may not remember in one to one interviews.



Therefore, a key characteristic of focus groups is the insight and data produced by the interaction between participants in response to planned questions. It has been identified that using focus groups has advantages over individual interviews, particularly when there may be power differences between the participants and professionals (Morgan, 1998). In this instance the participants have peer support and are more likely to be open in their replies to questions. Separate focus groups for staff and service users were held in this study to ensure the participants felt comfortable taking in a group.

#### *Limitations of focus groups*

Focus groups are limited in terms of their ability to generalise findings to a whole population, mainly because of the small numbers of people participating and the likelihood that the participants will not be a representative sample.

Another potential limitation of focus groups, particularly in mental health settings, is that the group format may discourage people from participating, for example those who are not very articulate or confident. The method of focus group discussion may also discourage some people from trusting others with sensitive or personal information. This highlights the need to acknowledge that focus groups are not fully confidential or anonymous, because the material is shared with the others in the group. For those participating in focus groups, there is always the possibility that intimidation within the group setting may inhibit interaction (Kitzinger, 1994).

#### *Methods to reduce the limitations*

To reduce the possibility of participants not speaking due to feeling unconfident about saying something different, the facilitator communicated clearly that there is no right or wrong answer, as well stating that every person's view is important. Additionally, in mental health research it has been found that participants who use mental health services relate and engage more in focus groups where the moderator has experience of using mental health services (Cook, Chambers & Coleman, 2009). Therefore a person with experience of using mental health services was selected to facilitate the focus groups.

### **3.2.2 Methods of analysis of focus groups**

Methods of analysis in qualitative research are often not well described, with studies often stating content analysis as a method without describing it in detail. This lack of detailed description of the procedures and rationale for their use can result in unreliable findings of the study. Qualitative research should demonstrate credibility of methods by adopting systematic processes to explain or verify the analysis (Green & Thorogood, 2004).

Thematic analysis was the method of analysis chosen for use in this study as it is a well-described systematic approach to analysis. It is a method for identifying, analysing and reporting patterns within data (Braun & Clarke, 2006). The theory and method for thematic

analysis has been comprehensively described by Braun and Clarke. Thematic analysis is not bound to a specific epistemological framework, and can be used as an essentialist/realist or constructionist method of analysis. The researcher therefore needs to ensure the theoretical position of a thematic analysis is clearly outlined, along with a description of the level at which themes are identified and how the themes were identified.

Identifying the epistemology framing a research question is important in ensuring clarity of purpose of study and justification of methods used. An essentialist/realist perspective indicates the researcher can theorize motivations, experience and meaning in a direct way, as within this perspective language reflects meaning and experience (Potter & Wetherell, 1987) Themes within the data are identified at the semantic level when using an essentialist/realist perspective (Boyatzis, 1998). In contrast, a constructivist perspective indicates that the researcher can theorise regarding the socio-cultural context, as within this perspective meaning and experience are socially produced rather than at individual level. Identifying themes using this perspective involves identifying latent underlying themes that shape the content of the data (Boyatzis, 1998).

In addition to stating the epistemological approach used for a study, the method of identifying themes using thematic analysis also needs to be explained. Braun & Clarke (2006) describe the two primary ways of identifying themes in the data as inductive and theoretical thematic analysis. An inductive approach means the themes identified are data-driven and therefore not driven by the researchers' theoretical interest in the topic. A theoretical approach to thematic analysis is driven by the researchers' theoretical or analytic interest, for example, a specific research question.

This study used a realist epistemology to examine the experience, and meaning attached to it, as described by the participants, relating to occupational performance following discharge from hospital. Theoretical thematic analysis was used to seek answers to questions relating to occupational performance following discharge from hospital.

Braun & Clarke (2006) outline six phases of analysis, which are described in Table 3.1

**Table 3.1 Summary of stages of thematic analysis**

Phase	Process
1 Familiarisation with data	Immersion in data by active reading and re-reading data, noting initial ideas for coding
2. Generating initial codes	Identification of interesting segments of data
3. Searching for themes	Develop potential themes by grouping codes generated in phase 2. Looking at relationships between codes and themes.
4 Reviewing themes	Level 1: Refining themes, collapsing or regrouping themes to create coherent meaningful themes and thematic map Level 2: Read data to ascertain if themes accurately represent data and code any items missed in earlier phases
5. Defining and naming themes	Refine themes and analyse data within them
6. Producing the report	Final analysis Write up, including data excerpts to tell story of data

#### *Quality and rigour*

Within the realist tradition, the researcher's task is to remain objective and provide a transparent methodological account. Much debate occurs between researchers regarding methods to assess rigour of qualitative research. It has been argued, that the concepts of reliability and validity as applied to quantitative research are not relevant to qualitative methods. Instead, the term trustworthiness has been used to ensure rigor in qualitative research (Lincoln & Guba, 1985). Lincoln and Guba describe four aspects of trustworthiness: credibility, transferability, dependability and confirmability.

Credibility has been defined as seeking to establish confidence in the "truth" of the findings, that is, the degree to which the findings make sense. Credibility can be built up through prolonged engagement in the field. It can also involve member checking to confirm accuracy of results. Member checking involves providing feedback of research data, analytical findings, interpretation and conclusions to participants to enable them to comment on how representative they are of their views. However, use of this method to enhance credibility has been called in to question. Sandelowski argues that because the stories told within interviews or focus groups reflect how the person viewed their lives at that moment in time, there when member checking

is carried out their views may have changed (Sandelowski, 1993). This argument holds true for the participants in this study who were recently discharged from hospital at the time of the study. Their perspective on the topics discussed in the focus group may have changed the longer they were discharged from hospital, and therefore member checking was not carried out in this study. Credibility was maintained by the inclusion of quotes from the focus group participants within each theme identified. The reader can therefore relate the findings to the direct quotes from the participants.

Transferability refers to providing as much detailed information and a rich description regarding the setting in which the research took place, so that the reader has enough information to judge if the findings are applicable to their settings. In this study, the transferability of findings was maximised by examining OP in a specific well-described context, following discharge from hospital. Therefore the findings are readily transferable to adults with a diagnosed psychotic disorder following discharge from hospital.

Dependability refers to the provision of documentation regarding data, methods and decisions made about the research. In this study dependability was enhanced by use of thematic analysis, which supports thorough and open reporting of philosophical and methodological decisions and the analysis process.

The final component, confirmability refers to the ability of the reader to confirm the findings oneself, through providing audit trail or pertinent data. Methods to enhance confirmability include use of a confirmability audit, audit trail, triangulation and reflexivity. An audit trail was used by the author, in this study. Summaries of all procedures regarding decisions made in the study and during analysis were kept, and process notes were kept regarding rationale for chosen methods.

### **3.3 Methods**

#### **3.3.1 Aims of the focus groups**

1. To explore the experiences of people with a diagnosed psychotic disorder following discharge from hospital regarding their occupational performance in the areas of self-care and leisure.
2. To explore the experiences of clinical staff regarding carrying out interventions to address everyday activities following discharge from hospital.

#### **3.3.2 Participants**

##### *Service Users*

Adults between ages of 18-65 with a primary diagnosis of a psychotic disorder, who have been discharged from hospital within the previous 3-6 months, were recruited to this study.

The inclusion criteria for participants of this study were:

1. Primary diagnosis of a psychotic disorder
2. Using community mental health services within South London & Maudsley NHS Foundation Trust.
3. Discharged from an adult acute inpatient mental health ward within previous 3-6 months.

Exclusion Criteria were:

1. Being unable to give consent,
2. too unwell to participate, as identified by named clinician
3. Requiring an interpreter to participate in the focus group
4. Substance misuse as primary presenting problem

### *Staff*

Occupational Therapists and Support Time and Recovery Workers with experience of working in the community with service users following discharge from hospital were recruited.

The Inclusion Criteria for staff participants to a focus group were:

1. Working in the community within South London & Maudsley NHS Foundation Trust
2. Recent experience (within last year) of working with individuals with a diagnosed psychotic disorder following discharge from hospital.
3. Occupational Therapists and STR workers delivering interventions to address difficulties of occupational performance.

### **3.3.3 Materials**

A person with experience of using both inpatient and outpatient mental health services was employed to moderate all the focus groups with the researcher present to take notes, and to ask supplemental questions as required.

Two topic guides were designed by the researcher, one for the staff focus group (found in Appendix 4 and one for the service user focus groups (found in Appendix 7). These were used to lead the discussions in the focus groups. Both topic guides contained three main questions with prompt questions relating to each of the three questions to elicit more detailed answers if required. The questions related to experiences of the participants' engagement in occupational performance during the six months following discharge from hospital. Clinical staff were additionally asked questions relating to intervention approaches they used to address problems identified.

### **3.3.4 Procedure**

NHS Research Ethics Committee approval for the pilot study was received in from the National Research Ethics Service Committee London – East (REC reference: 10/H0807/69), a copy of

which can be found in Appendix 1. Research and Development approval was obtained from the NHS Trust hosting the focus groups.

#### *Service user focus groups*

Participants were recruited from community mental health services for adults with a diagnosed psychotic disorder in three Boroughs within South London & Maudsley NHS Foundation Trust in South East London. Care co-ordinators and team leaders identified and contacted service users who met inclusion criteria for the study to explain the study to them, provided them with an information sheet (Appendix 5) and offered them the opportunity to meet with the researcher to clarify any aspect of the study prior to deciding to take part in the study. Consent forms were signed by the participants on the day of the focus group, before it commenced. The service user participants each received a £20 multi-shop voucher to compensate them for their time. Two service user focus groups took place.

#### *Staff focus group*

The clinical staff were recruited by inviting all OTs and STR workers in community mental health teams working with people with a diagnosed psychotic disorder, to participate in focus groups. The staff were given a copy of the Participant Information Sheet (Appendix 2) and given the opportunity to ask the researcher any questions, before deciding to take part in the study. They were given Consent forms were signed by participants on the day of the focus group, before it commenced.

The focus groups took place in a community mental health team base and lasted for one hour. The focus groups were transcribed by the author and each focus group analysed separately. All participants named were changed to pseudonyms during transcription to protect the identity of the participants.

### **3.3.5 Analysis**

As outlined in Section 3.2.2, thematic analysis was the method used to analyse the data. Theoretical thematic analysis was done across all the questions for each focus group, rather than each specific question asked, to enable identification of themes across the data. Themes were identified at a semantic level, that is, at the surface level of meaning of what participants said. The researcher followed the phase of analysis as outlined in Table 3.1.

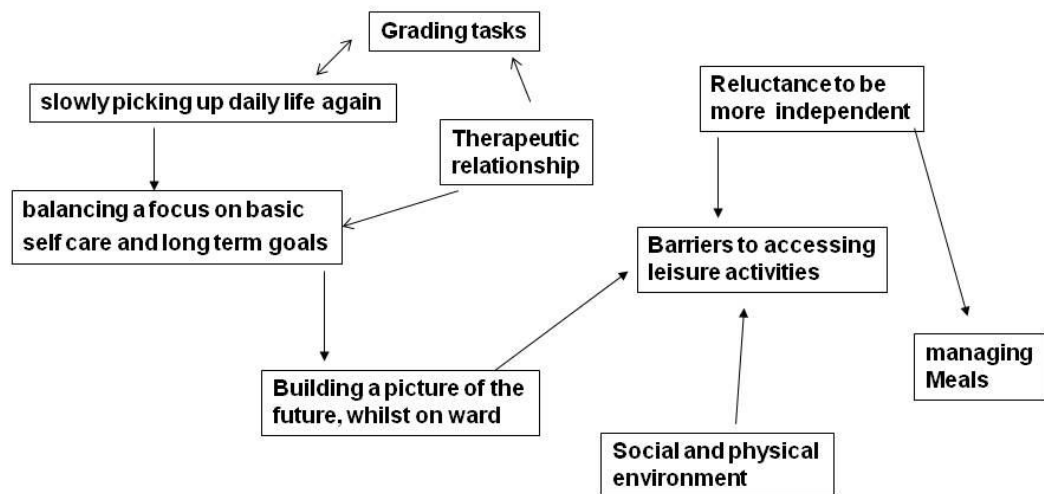
The themes were developed separately for each focus group as it became apparent that the discussions in all three focus groups varied. Themes were developed regarding the problems of occupational performance for people with a diagnosed psychotic disorder following discharge from hospital and interventions to improve occupational performance post discharge from hospital. The themes from all three focus groups were then examined together to analyse the similarities and difference between the themes from each group.

### 3.4 Results

Three focus groups were held over a two month period. Six service users participated, comprising, one female and three males in Focus Group One, and two male service users in the Focus Group Two. Three Occupational Therapists and one STR worker took part in the staff focus group.

Figure 3.1 outlines the thematic map of the final themes identified relating to occupational performance following discharge from hospital for all three focus groups.

**Figure 3.1 Thematic Map of Occupational performance following discharge from Hospital**



The themes identified from each focus group will be described next, to represent the descriptions of occupational performance as they were expressed in each focus group.

#### 3.4.1 Themes from Service User Focus Group One

This focus group consisted of two males. Joe lived in 24-hour supported accommodation and Simon lived in a shared house for people with mental health problems. Three themes were identified on analysis of the data from this focus group.

##### *Theme 1: Reluctance to be more independent post discharge*

Participants in this group liked the experience of being dependent on staff for meals and to organize their day whilst an inpatient.

**Joe said:**

*"I liked the routine of it (hospital), you've got a structure there, you don't have to think for yourself"*

Joe further described his desire to be in a structured dependent environment:

*"Yeah it's a bit of a struggle that leaving hospital cos that's one part I was struggling with. I mean I wish I was back in hospital cos I prefer it I think"*

For Joe, leaving hospital meant he would have to leave the structure and routine for a less structured environment. This directly impacted on his daily routine and occupational performance:

*"I find it hard getting up in the mornings- why? The fact that I have to arrange it (waking up) myself"*

Simon, did not share Joe's wish to stay on the ward, he found he had to adjust to an environment where he had to carry out more activities of daily living himself on discharge:

*"laundry was a bit hard because I had to pay for it."*

Simon had to budget to organise his laundry, something he did not have to do on the ward.

Both participants describe their dissatisfaction with a reduction in support to maintain a daily routine.

#### *Theme two: managing meals*

Reduction in meal provision was identified as a concern by Simon following discharge from hospital:

*"Meals, they were providing only breakfast and yet in hospital they used to provide us with breakfast, lunch and supper."*

Simon also stated that he didn't want to cook his own meals, which also had implications:

*"cooking is not my thing- I was forced to get take-aways"*

Joe also found it difficult to eat three meals a day following discharge as he did not wake up in time to have breakfast in the hostel.

Simon felt a solution to managing meals was as follows:

*"they should have taken me to a place where meals are provided"*

However Simon stated that after a few months:

*"I'm beginning to get used to doing things for myself"*



Both contrasted their reliance on meals being provided and support to attend for meals whilst on the ward, with their post-discharge experience, of organising three meals with a lower level of support.

#### *Theme three: Barriers to accessing leisure activities*

Since leaving hospital Joe stated that whilst he would like to go to a gym, he hasn't done this yet. He described the reason why:

*"my mate used to go to the gym with me, but he left the hostel, there's no one that goes to the gym, so that's one reason -why (he isn't going to the gym)"*

Simon described a different reason for not doing leisure activities in the community, despite identifying football and meeting people as activities he would like to do:

*"I don't know where to go."*

Joe did access some community groups run by mental health services and indicated the role community mental health staff played:

*"Yeah, they're good for motivation; they're good at inspiring me to do stuff. They give lots of encouragement."*

Both Joe and Simon identified leisure activities they would like to do in the community, but neither had actually done so. This could indicate a lack of skills to do so, or lack of motivation to initiate such activities and explore their local communities. Simon indicated a lack of knowledge of resources had prevented him and Joe similarly indicated a lack of knowledge regarding support to access leisure such as peer support.

### **3.4.2 Themes from Service User Focus Group Two**

This focus group consisted of four Service users. Michael lived in shared accommodation with five other people. Susan lived with her parents, as did Neil. Steven lived in a rented flat. Two themes were identified.

#### *Theme one: slowly picking up daily life again*

The participants in this group describe a process of gradually picking up aspects of daily life again following discharge from hospital.

Michael said:

*"every time I go into hospital I go down- it's like I have to build myself back up again, so month one is kind of slow for me, then month two I start to pick up, and three I've reached a bit further."*

He adds:

*"I take it month by month, day by day" "slowly getting to where I want to be, to be able to do that course"*

Michael describes how each admission sets him back in terms of his ability to maintain his daily routine and progressing in education. The experience of being in a high support environment on the ward appears to disrupt the service users' routine and ability to progressively work towards goals.

*Sub theme: being able to do more by three months post discharge:*

Several participants described that by three months after discharge from hospital they were able to do more with their time. Susan stated:

*"I was able to go shopping and go out a lot more, with friends and family"*

Steven also reported that he was more active:

*"I got more involved in the church"*

Michael described:

*"in two to three months after leaving hospital then it starts to pick up and you get back into your routine"*

All participants indicated that they were able to build up their activities by three months following discharge from hospital, with one participant indicating they had returned to their usual routine. However, this may involve a return to the level of daily occupational performance they had during the months leading up to admission, which may not have been to their satisfaction at the time. Therefore following discharge they may wish to change their daily routine to incorporate new occupations and re- introduce previous occupations.

*Theme Two: Building a picture of the future post discharge, whilst on the ward*

Participants in this group found that whilst still an inpatient they were able to begin to think about changes they'd like to make to their life following discharge:

*"They run a football group, in the hospital, they have all kind of activities- it helps you get a picture in your head of when you come outside you can do these kind of activities to help you as well"*

Neil stated:

*"On the ward, someone mentioned about the music group, and told my care co-ordinator who then referred me there- I'm grateful that they mentioned it whilst I was on the ward"*

The opportunity to think ahead about the future following discharge from hospital appears to benefit the participants by increasing knowledge of what is available and what they may like to do.

### **3.4.3 Themes from staff focus group**

This focus group consisted of four participants who were clinical staff working with community mental health services within a local NHS trust. Amy, Helen and Rita were Occupational

Therapists and Karen was a Support Time and Recovery Worker with experience of working with service users with a diagnosed psychotic disorder following discharge from hospital.

#### *Theme one: Therapeutic relationship*

All participants highlighted the significance of the therapeutic relationship with the service users following discharge from hospital, and in particular how they would change their therapeutic use of self at different stages of working with the service user.

An example of this was carrying out a task alongside the service user to provide initiation for the task at a time when the service user was overwhelmed by the number of tasks following discharge from hospital:

Helen said:

*"I'd roll up my sleeves and say to them (service user), 'come on, shall we clean your fridge out cos your milk has been in there for a month'".*

By carrying out the task with the service user, the clinicians encourage the service user to actively contribute to the task without expecting them to be autonomous in the task at this stage. The clinician instructs the service user regarding strategies to clean fridge.

An example of how the clinician purposefully changed the therapeutic relationship when the time was right was given by Helen:

*"I'm handing it back to you now (service user), I won't be going to the shop with you..... so when do you think you are going to do your shopping in the week?"*

The clinician purposefully did less of the task with the service user and worked more collaboratively with the service user over time. Participants also outlined the importance of their therapeutic relationship in enabling them to work with service users on sensitive aspects of self-care:

Amy said:

*"creating a safe honest environment where you can give that feedback (food spilt on clothes) and its modelling and thinking about 'so how often do you wash your clothes'"*

The clinical staff described how they are continuously aware of their therapeutic relationship with the service user and change their therapeutic use of self as they feel appropriate to the situation.

#### *Theme two: Grading tasks*

The participants acknowledged that due to service users being unwell prior to admission they may return home to a neglected home environment. Rita stated:

*"things have been tricky before that (admission) and then there's that aftermath"*

As a result of this aftermath and recovery time following relapse, participants felt it was important to support service users to slowly tackle the large number of tasks needed in their homes following discharge from hospital. Helen stated:

*“people sometimes need a bit of a head start or a helping hand to get the momentum going”*

By grading and adapting the tasks needing to be done by the service user, it made it easier to complete all the tasks successfully over time. For example, with regards to grading the task of meal preparation, Amy stated:

*“you might start by making sure there’s food in the fridge or microwave meals and then further along thinking about any simple meals they would like to cook.”*

After three months post discharge the staff participants began to be less actively supporting people and spoke of *“up skilling people”* so that they could carry out self-care tasks more independently where possible.

The participants in this focus group describe how they would grade a task by suggesting tasks to prioritize, initiating tasks and doing the activity alongside the service user to start the tasks.

#### *Theme three: balancing a focus between basic self-care and long term goals*

The staff in this focus group described how in practice they have prioritised self-care needs with service users following discharge from hospital:

Rita, OT said:

*“I guess there’s a Maslow’s hierarchy of need: you are sorting out the basic needs and then you can move onto the things with meaning.”*

The participants also outline how they, whilst supporting them with basic self-care, bear in mind the goals and future ambitions service users:

Helen, OT Said:

*“kind of holding onto what the goal was that might be a vocational one or something-fostering motivation for that”, “paying attention to that”*

In thinking about long term goals the participants identified another strategy they used to support individuals to think about their needs and goals:

Helen, OT said:

*“I always think, so much of our role is about making lots of suggestions that people can take or not!”*

In linking the basic self-care tasks with future goals of the participants describe the service users’ overall lifestyle:

*“it’s more the habit and routine that people often talk about”*

The participants describe the importance of establishing a routine to participate in a range of occupations beyond basic self-care. The clinical staff participating in this focus group identified how they supported service users with basic self-care tasks as a priority post discharge, whilst thinking ahead with them regarding longer term goals.

#### *Theme four: Social and Physical Environment*

As has been previously described, the staff participants identified that the service users often return home from hospital to find their home environments chaotic:

*“going back to somewhere where you’d been unwell before and it’s quite chaotic.”*

The staff participants also identified the need for service users to adjust to different environments:

*“the ward is such a safe and protective environment... the person has to readjust to being in a different environment on discharge”*

The participants identified that there may be barriers to occupational performance within the persons’ social environment, for example:

*“they were quite embarrassed and didn’t want to meet neighbours and be asked where they’d been or to be asked how they are- this was a barrier to the person getting out and about on their estate”*

The participants also highlight the importance of the local environment in supporting the service users’ optimal occupational performance, in the long term.

*“you can become very much a safety net for them and it’s how you transfer that support to other activities in the community”*

The participants in this focus group described how the service users’ physical and social environment impacts on their ability to carry out daily living skills and leisure in their homes and in their local community.

#### **3.4.4 Connections between themes across the three focus groups**

Connections between themes were found across all the focus groups, these connections further aid understanding of the experience of occupational performance following discharge from hospital.

#### *Developing occupational performance is a slow process*

The themes picking up goals, balancing self-care with long-term goals, and grading tasks are inter-related. Grading tasks describes the approach used by staff and service users to slowly pick up goals again, focusing on self-care initially. Once basic self-care tasks such as managing meals are carried out to the persons’ satisfaction, then the participants’ began to look at longer term goals such as attending a course or finding a job, as well as slowly picking up other aspects of daily life. One interpretation of this is that staff were following their duty of care to ensure service user could carry out the basic tasks, such as meal provision, following discharge

from hospital. However the staff report the importance of establishing a routine, indicating that they view the establishment of basic self-care routine as a significant step to engaging in leisure occupations.

#### *Social and physical environment*

The clinical staff described aspects of the environment that can affect occupational performance following discharge. The impact of a persons' environment on occupational performance has been identified by staff and service users. In particular, service users identified both social and physical environmental barriers to accessing leisure in the form of lack of social contacts and a lack of knowledge of the local environment. In a study of community functioning in young adults with recent-onset psychosis, as described in Section 2.3.4, participants experienced social isolation after being re-housed in unfamiliar neighbourhood as they did not know anyone locally and were unfamiliar with community resources (Roy et al., 2009). A focus on environmental assessment and considerations is required for interventions to improve occupational performance following discharge from hospital.

#### **3.4.5 Difference in themes across all three focus groups**

Three themes differed across the focus groups: reluctance to be more independent after discharge, therapeutic relationship and building a picture of the future following discharge, whilst still on the ward.

#### *Reluctance to be more independent after discharge*

Participants in Focus Group One found the transition from hospital to home a challenge, because in-patient staff maintained a daily routine and provision of meals on the ward. This theme suggests that in attempting to provide care for patients during the acute phase of their illness, dependency may inadvertently be created. One explanation for this participant's view is that he has adopted a view of his personal identity as a patient and passive recipient of care. Interventions to improve occupational performance will need to include the service users' perspective and support motivation for occupational performance.

#### *Managing meals*

Service user participants reported that initially they were not keen on organising meals for themselves following discharge from the ward. Additionally it took them some time to be able to initiate meal provision and budget for this also. This highlights the need for assessment and discussion, whilst the service user is still on the in-patient unit, regarding independent living skills such as cooking. This would support the service user to consider what they would be expected to do independently and ensures service users are prepared and can plan for meal provision on discharge. An example of this would be that in the community, unlike the ward, no one wakes the individual in time for breakfast, so they would need to consider how to manage that, along with budgeting for meals.

#### *Building a picture of the future post discharge, whilst on the ward*

Service users in Focus Group Two stated the inpatient programme of leisure opportunities helped them sample activities that they may like to start doing or return to in the community following discharge. This helped them to think ahead and make plans for how to spend their time post discharge. For these participants they were looking forward to life outside the ward and choosing how they would spend their time. The service users in the first group experienced the inpatient environment differently, where they did not consider how they could independently engage in leisure activities in the community but rather enjoyed that staff facilitated all activities for them. It could be that the two wards that the participants were on were very different in their provision or in their explanation of rationale for leisure activities whilst on the ward.

#### *Therapeutic relationship*

The staff participants in this study emphasised the importance of being consciously aware of the therapeutic relationship with service users and adjusting their therapeutic use of self as required. The service user participants however, did not discuss the role of staff in great detail with only Joe and Simon stating how community mental health staff helped them gain motivation to take part in activities. Service user participants on the other hand did not refer to any negative experiences they have had when encountering staff.

Two themes differed across the focus groups, reluctance to be more independent post discharge and building a picture of the future post discharge, whilst on the ward. These two themes may be linked in that for those service users who had the opportunity to sample community resources and then build a picture of the future on the ward, they were also able to engage in community resources. It highlights the importance of planning for daily life post discharge, whilst on the ward.

### **3.5 Discussion**

Nine inter-related themes were identified in this study in relation to improving occupational performance following discharge from hospital; therapeutic relationship, grading tasks, slowly picking up daily life again, balancing a focus on basic self-care and long term goals, building a picture of the future whilst on the ward, reluctance to be more independent, barriers to accessing leisure activities, social and physical environment and managing meals.

The importance of the role of the therapeutic relationship in clinical interventions is well documented (Priebe and McCabe, 2006). Users of mental health service have indicated that it is an important component of good clinical services (Johansson & Eklund, 2003) additionally the concept of therapeutic use of self is well documented within occupational therapy literature as a key component of occupational therapy practice (Taylor, 2008). As a result of a lack of detail regarding how therapeutic use of self is defined and implemented, Taylor published The

Intentional Relationship Model, to define the therapeutic use of self within occupational therapy practice (Taylor, 2008). This model can be usefully incorporated into interventions to improve occupational performance to outline the therapeutic relationship component of the intervention.

The concept of setting short term goals in order to reach longer term goals regarding occupational performance can be found within occupational therapy literature (Creek, 2010). The findings of this study indicate that this is an important concept for clinical staff and service users to focus on to improve occupational performance following discharge from hospital. Activity analysis and grading, are clinical techniques documented within occupational therapy literature since the profession began in the 1900s (Hersch, Lamport & Coffey, 2004). These are in use in occupational therapy clinical practice within mental health and can be tailored within an intervention post discharge from hospital.

The difference regarding experience of discharge planning whilst on the acute ward indicates that leisure activities facilitated by staff for inpatients need to be explicit in their aim of providing links with community resources. This should incorporate strategies for engaging in these activities post discharge. One solution would be for an intervention aimed at improving occupational performance post discharge, to commence whilst service users are on the inpatient unit. This would provide a seamless transition from hospital to home regarding improving occupational performance. The provision of leisure and meaningful occupations is acknowledged as an important element of inpatient care. Many leisure activities can provide the opportunity to sample community activities, information about the facilities and support access to the facilities post discharge. The findings from this study highlight the importance of making explicit the role of inpatient leisure activities in sampling the range of leisure activities in the community.

Managing meals was identified as a difficulty, in addition to other problems regarding returning to self-care on discharge. The clinicians stated that a graded approach could be used to support improvement in this area over time, whilst meeting basic needs to eat and manage home.

The participants in this study described problems in the social and physical environment that created barriers to accessing community leisure facilities. This theme was also identified in Section 2.3.4. This further strengthens the importance of an intervention to address the impact of the environment on OP, both in the home and the community.

### **3.6 Conclusion**

#### *Implication for clinical services*

The findings of this sub study have implications for mental health service provision regarding facilitating discharge from hospital. The findings highlight the need for interventions in inpatient setting to prepare for discharge. Systems need to be in place to ensure all patients increase the



use of their independent living skills on the ward, as they recover from clinical crisis. Such an approach would decrease the opportunity for service users to become dependent on staff to structure their day and to attend to self-care needs. This could be done through the establishment of regular opportunities to carry out daily living skills whilst still an in-patient, such as a supper club, ward chores, and exploring local cafes and other resources nearby. Sampling of leisure occupations whilst on the ward and opportunity to discuss how to access the resource or similar following discharge is also an important component to include. Regular discussion regarding community living in reference to establishing a daily routine, including meals and other self-care tasks will also enable the service users to prepare for discharge. To support engagement in leisure activities post discharge, leisure activities organised with staff need to explicitly support choice and community considerations.

#### *Implications for the intervention*

The results of this sub study indicate the need for the inclusion of several components when developing an intervention to improve occupational performance following discharge from hospital. Table 3.2 outlines the findings of this study and the implications for the development of the intervention.

**Table 3.2 Summary of findings of focus groups and implications for intervention.**

<b>Finding</b>	<b>Implication for Intervention</b>
Grading tasks	Use of activity grading as a component
Therapeutic relationship	Use of The Intentional Relationship Model
Slowly picking up daily life again	Use of activity grading as a component
Balancing a focus on basic self-care and long term goals	Use of activity grading as a component Identification of valued occupations and service user led goal setting Stepped intensity approach to resolve urgent self-care needs following discharge followed by reduced intensity focus on community and leisure
Building a picture of the future whilst on the ward	Start intervention prior to discharge from hospital
Reluctance to be more independent	Use of a theoretical model of improving motivation for occupation, and occupational performance Assessment of OP included in the intervention Emphasis on development of self knowledge and self management of own OP
Barriers to accessing leisure activities	Assessment of OP included in the intervention Intervention to take place in relevant community venue Use of Interest Checklist
Social and physical environment	Use of strategies to overcome physical barriers in home environment Use of strategies to overcome social environmental barriers
Managing meals	Use of strategies to overcome physical barriers in home environment Use of activity grading as a component

The findings of this sub-study and implications for the intervention will be synthesised with the findings of the three other sub-studies to develop the intervention, this is presented in Section 6.2.1.

# Chapter 4 Interventions to improve occupational performance: systematic review

## 4.1 Introduction

This chapter reviews current evidence regarding interventions to improve occupational performance for people with a diagnosed psychotic disorder. The MRC framework identifies that a review of the existing evidence regarding interventions to address the area of clinical need identified, is an important component of developing a complex intervention (Medical Research Council, 2008). This chapter consists of sub-study three, a systematic review of studies of interventions to improve occupational performance for people with a diagnosed psychotic disorder. This will support the identification of suitable interventions to inform the development of an intervention for use in stage two of the study (Pilot) Chapter 6 presents the development of the intervention.

Chalmers and Altman (1995) define a systematic review as a review that uses a systematic approach, which minimised biases and random error, and which documents the approach in a materials and methods section.

The purpose of a systematic review is to evaluate and interpret all available research evidence relating to a specific question. The current number of medical, nursing and allied healthcare professional journal publications makes keeping up with primary research evidence a challenge for researchers and clinicians. Therefore the rigorous collection and interpretation of available knowledge regarding a topic is essential to inform research and clinical practice. A systematic reviews may also demonstrate the lack of adequate evidence and thus identify areas where further studies are needed (Egger, Smith & Altman, 2008).

## 4.2 Rationale

Little is known regarding what interventions to improve occupational performance have been studied and what evidence they present. National Institute for Health and Clinical Excellence (NICE) Guidelines on the core interventions in the treatment and management of schizophrenia (National Collaborating Centre for Mental, 2010) recognises that a significant number of people with schizophrenia experience long-term impairments, with personal, social and occupational impacts. The guidelines include a section on psychosocial interventions but do not include interventions to improve occupational performance. A review by the Cochrane Collaboration of life skills programmes for chronic mental illness identified four randomised controlled trials (RCTs) evaluating life skills programmes versus standard care or a support group (Tungpunkom & Nicol, 2008). They defined the components of life skills as communication, financial

awareness, competence in domestic tasks and personal self-care. The results of the review found no significant difference in life skills performance between the groups. A systematic review of the evidence from systematic reviews regarding efficacy of occupational therapy in different conditions identified an early version of the systematic review by Tungpunkom and Nicol (Steultjens et al., 2005). The systematic review by Steultjens and colleagues did not find any other reviews regarding interventions to improve occupational performance for people with a diagnosed psychotic disorder.

It is recognised that published systematic reviews have largely focused on the synthesis of quantitative evidence of effectiveness, especially in Cochrane reviews. However, a wider range of systematic review questions are now being used (Gough, Thomas & Oliver, 2012). The Cochrane Handbook for Systematic Reviews of Interventions acknowledges that including only randomised controlled trials (RCT) study designs can compromise the relevance and utility of the review (Higgins & Green, 2011). For example, studies showing positive effects of thoroughly developed interventions, using less rigorous methods than RCTs, may merit further research. Given the absence of reviews of OP for people with a diagnosed psychotic disorder, the review presented in this chapter includes a wide range of study designs to ensure all interventions studied were found and critically appraised. The review aims to identify and characterise studies of interventions to improve OP. The results will enable researchers and clinicians to make decisions regarding which interventions warrant further investigation or are suitable for clinical application.

### **4.3 Aims**

The aim of this review was to characterise the evidence for interventions to improve occupational performance in adults with psychotic disorders in a community setting.

The objectives were:

1. To identify and characterise studies of interventions to improve occupational performance
2. To characterise the theory base, level of standardisation and treatment fidelity for identified interventions

### **4.4 Methods**

#### **4.4.1 Eligibility Criteria**

##### *Types of Study*

Randomised controlled trials, quasi-experimental studies, observational studies, and qualitative studies.

#### *Types of Participants*

Participants aged between 18 and 65 with a diagnosis of schizophrenia or schizoaffective disorder (or at least 70% of sample) living in the community.

#### *Types of Interventions*

Studies of interventions which primarily aim to improve occupational performance, excluding vocational occupations.

#### *Types of Outcome measures*

The primary outcome is occupational performance.

### **4.4.2 Data Sources**

Three data sources were used: online databases, internet search and a hand search. Online database searches were carried out in January 2011. The online databases searched were CINAHL, PsycINFO, Medline, ASSIA and Embase databases, the Cochrane Library, OTCATS (Occupational Therapy Critically Appraised Topics), OTseeker, and online databases of unpublished PhD and Masters' theses available from the College of Occupational Therapy and the Institute of Psychiatry. The internet search using Google was carried out using the same search terms that were used in databases, to identify grey literature and conference proceedings relating to psychosis and occupational performance.

The table of contents of the following publications were also hand searched: Schizophrenia Bulletin, Schizophrenia Research, Psychiatric Services, British Journal of Occupational Therapy, Occupational Therapy in Mental Health and Occupational Therapy Journal of Rehabilitation.

#### *Search strategy*

Test searches were undertaken to test identified search terms against the indexed terms, subject heading terms or MeSH (Medical sub-Headings) terms in each database. The search terms identified as being most effective in finding key papers and papers relevant to search were used to search the databases. Table 4.1 outlines the terms used to search CINAHL.

**Table 4.1 Search terms used in CINAHL database**

	<b>Search term</b>
Population	Schizophrenia OR Psychotic disorders OR Affective disorders, Psychotic OR Severe and enduring mental health AND community
Intervention	Leisure activities OR functional status OR community integration OR self-care OR activities of daily living OR skill acquisition OR skill retention OR meal preparation OR occupational performance OR occupation* AND performance OR participation OR engagement OR functioning OR impairment or adaptation
Design	Intervention AND study OR evaluation OR Pilot study OR Randomised Controlled Trial
Outcome	Change in occupational performance OR skill* acquisition

A search using variations of these terms appropriate to the terms used in the databases was carried out in each of the five databases, mapped and unmapped against indexed subject heading. The search strategy was restricted to studies published since 1995 and English language only. Searches were recorded as they were carried out, and identified references saved in Reference Manager Software Version 11.

#### *Study selection*

The selection process was piloted by applying the inclusion and exclusion criteria to a sample of papers identified as likely to be included. This was done in order to check that the inclusion criteria were reliably interpreted and that they classified the studies appropriately. The pilot stage was also used to refine and clarify the inclusion criteria.

Abstracts of identified papers were initially assessed for eligibility by the author. For studies not excluded on abstract, the full paper was obtained and assessed in more detail against the inclusion and exclusion criteria. A second rater was used to independently assess the eligibility of a random selection of 20% of full papers, to estimate concordance on inclusion. The flow diagram from the PRISMA reporting guidelines was used to display the study selection process (Moher et al., 2009). A record of decisions made for each article retrieved as full text was kept in the form of a database of all studies and reasons for inclusion or exclusion.

#### **4.4.3 Data Extraction Process**

The following data items were extracted from each paper included in the study:

Country the study took place

Study design

Population described in study

Intervention description:

Theoretical base

Level of standardisation

Fidelity assessment

Control description

Outcome measures

Data were collated on data extraction sheets, shown in Appendix 8.

### *Quality Appraisal*

Appraisal of quantitative methodologies was carried out using the Quality Assessment tool for quantitative studies (Effective Public Health Practice Project, 2009). This tool involves rating studies as methodologically strong, moderate or weak in six sections: selection bias, study design, confounders, blinding, data collection method and withdrawals and dropouts. A single quality rating is then calculated by rating studies with no Weak ratings as Strong, studies with one Weak rating as Moderate and studies with two or more weak ratings as Weak. A reviewer's dictionary is provided to assist reviewers and maintain standardised results. Quality assessment was double rated for 50% of the studies.

### *Evaluation criteria*

Each study was examined using the criteria presented in Table 4.2

**Table 4.2 Criteria for evaluation of studies**

<b>Criterion</b>	<b>Rationale</b>
Psychometric properties of outcome measure	Use of standardised measures reduces measurement error and increases validity.
Cost effectiveness analysis (CEA)	The cost effectiveness of an intervention is an important consideration in healthcare and research, therefore where reported, this was examined.
Theory base of the intervention	The MRC Framework states that complex interventions with a theoretical basis are more likely to be effective than those without a theoretical base (Medical Research Council, 2008).
Treatment fidelity	the characteristics of the interventions studied require examination, as the validity of the results will be influenced by the quality of the intervention being studied (Medical Research Council, 2008).
Treatment manual	The interventions in the study should be described with sufficient details to allow replication (Moher, Schulz & Altman, 2001).

#### **4.4.4 Data analysis**

Analysis of intervention studies in a systematic review involves analysis of the results of included primary studies. The recommended analysis is quantitative techniques, involving statistical analysis (Higgins & Green, 2011). Meta-analysis is the statistical combination of results from two or more separate studies and is the most commonly used statistical technique in systematic reviews. Forest plots are used in meta-analysis to display effects estimates and confidence intervals for each study and also to display a pooled effect of all the studies combined. The Cochrane handbook for systematic review warns that meta-analysis can be misleading if attention is not paid to the studies being combined. Studies that are clinically diverse, and have different comparisons, for example such as those found in systematic reviews with a wide scope, are not suitable for meta-analysis. Additionally, the handbook outlines that combining results of studies that are at risk of bias is not appropriate as an inaccurate result will be produced. In such cases narrative synthesis can be used to outline the effects of the interventions.

Narrative synthesis was used to integrate the results of studies included in the review, as the studies were clinically diverse, used a range of outcome measurement tools and were shown to have a range of comparisons. Narrative synthesis refers to a process of synthesising primary studies to explore heterogeneity descriptively rather than statistically. The narrative synthesis used in this study consisted of three stages (Roberts, 2007). The first stage was to organise the studies into logical categories, which was done by tabulating the results according to focus of intervention. The second stage involved analysing the findings within each category. The third stage consisted of exploring relationships within and between studies, thereby synthesising the findings across all included studies.

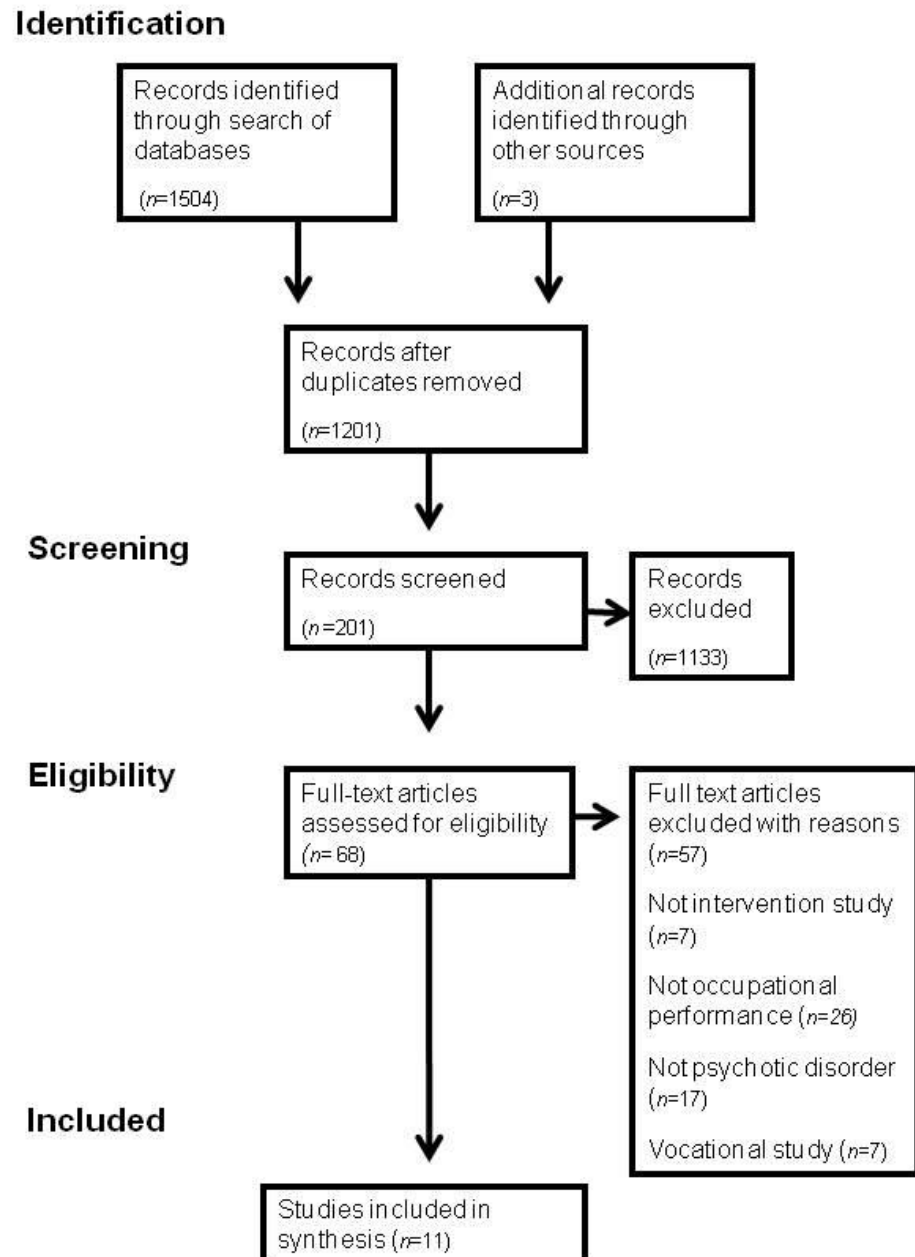
### **4.5 Results**

#### **4.5.1 Study selection**

The searches were carried out in January 2011 and resulted in 1,507 papers being found. Following assessment of papers against inclusion criteria 11 papers were included in the review. A summary of the stages of the review following the Prisma flow diagram is presented in Figure 4.1.



**Figure 4.1 Prisma flow diagram**



#### **Excluded studies**

1133 papers were excluded from the review. The 57 studies excluded after reviewing the full text did not meet the inclusion criteria for the following reasons: the required percentage of study participants were not adults with a diagnosed psychotic disorder (n=17), interventions were not primarily aimed at improving occupational performance (n=26), and studies did not

focus on an intervention (n=7). Seven of the full text articles were excluded as they were studies of vocational occupations.

#### **4.5.2 Narrative Synthesis Stage One: Organisation of included studies**

Eleven studies were included in the review. All 11 studies used quantitative methods and a range of study designs to investigate interventions to improve occupational performance. The focus of intervention and outcome measures used varied between studies. Interventions were grouped by the descriptions of the interventions into five categories: Occupational Therapy; life skills; meal preparation; role development; and integration of tasks with cognitive ability. Characteristics of the individual studies are shown in the Table 4.3.

Table 4.3 Summary of Included studies													
Study	Author Year	Country	Intervention	control	Design	Sample	Population	Primary Outcome	Quality Rating	Weak Components			
<b>Category 1: Occupational Therapy</b>													
1	Buchain et al, 2003	Brazil	Occupational Therapy AND Clozapine	Clozapine	RCT	18	Adults with treatment resistant schizophrenia	Scale for Interactive Observation in occupational therapy (EOITO)	Weak	Confounders Blinding Data collection tool not valid or reliable			
2	Cook et al 2009	England	Occupational Therapy for people with psychosis in community setting	Treatment as usual	RCT	44	Adults with diagnosed psychotic disorder of any duration	Social Functioning Scale (SFS)  Scale for assessment of negative symptoms (SANS)	Strong				
3	Cook & Howe 2003	England	Occupational Therapy: based on PEOP model	N/A	pre-test post-test	37	Adults with psychosis	Social Functioning Scale (SFS)	Strong				
<b>Category 2: Life Skills</b>													
4	Liberman et al 1998	USA	Life skills training V psychosocial OT	Psychosocial OT group work	RCT	80	Adults with persistent and unremitting forms of schizophrenia	Independent Living Skills Survey (ILSS) Social activities scale (SAS) Profile of adaptation to life Global assessment Scale (GAS) Rosenberg self esteem scale Lehman quality of life scale	Moderate	Confounders			

Table 2.3 Summary of Included studies										
Study	Author Year	Country	Intervention	control	Design	Sample	Population	Primary Outcome	Quality rating	Weak Components
5	Mairs & Bradshaw 2004	England	Life skills programme	N/A	Pre- test Post-test	17	Adults with diagnosis of schizophrenia or schizoaffective	Positive and Negative Syndrome Scale (PANSS) Social Functioning Scale (SFS)	Strong	
Category 3: Role Development										
6	Schindler, 2008	Israel	Role development to increase task and interpersonal skills and social roles	N/A	Pre-test Post-test Case study	10	Adults with diagnosis of schizophrenia from 4yrs to 20yrs duration	Role Functioning Scale Task skills scale Interpersonal Skills Scale	Moderate	Blinding
Category 4: Meal Preparation										
7	Brown et al, 2002	USA	Improving grocery shopping by providing strategies that organize and simplify the task and environment	N/A	Pre-test Post-test	43	Adults with schizophrenia or schizoaffective	Test of Grocery Shopping Skills	Weak	Blinding Withdrawal and dropouts
8	Duncombe 2004	USA	Learning of a functional living skill- cooking, in clinic V home	Cooking in clinic	Non-randomised Controlled trial	44	Adults with schizophrenia or schizoaffective disorder for at least 5 years	Allen Cognitive Level Screen (ACLS-90) Kitchen Task Assessment-Modified	Weak	Confounders Withdrawals and dropouts

Table 4.3 Summary of Included studies										
Study	Author Year	Country	Intervention	control	Design	Sample	Population	Primary Outcome	Quality rating	Weak Components
Category 4: Meal Preparation (continued)										
9	Porter et al, 2000	Australia	An individualised food-skills programme	N/A	Pre-test Post-test Case study	3	Adults with schizophrenia over 20years	Functional Needs Assessment-Nutritional Management Programme (FNA-NMP)	Moderate	Data collection tools: reliability and validity not reported
10	Grimm et al, 2009	USA	Acquisitional frame of reference (FOR) and psycho educational to improve meal preparation Versus OT intervention using acquisitional FOR only.	Acquisitional frame of reference only	RCT	8	Adults with diagnosis of subtype of schizophrenia or schizoaffective	Performance Assessment of Self-Care Skills (PASS)	Weak	Confounders Withdrawals and drop outs
Category 5: Integration of tasks with cognitive ability										
11	Raweh & Katz, 1999	Israel	Intervention based on Allen's Cognitive Disabilities Model	Working in a community activity centre	Non-randomised controlled trial	19	Adults in post acute stage of schizophrenia	Brief Psychiatric Rating Scale (BPRS) Allen Cognitive level screen (ACL-90) Routine Task Inventory (RTI-2) Awareness Questionnaire	Weak	Blinding Data collection tool: reliability and validity not reported for RT1-2)

### 4.5.3 Narrative Synthesis Stage Two: Analysis of findings within each category

The findings within each category will now be evaluated.

#### *Category 1: Occupational Therapy*

Three interventions were described as Occupational Therapy. Table 4.4 summarises the interventions and results of the studies.

**Table 4.4 Summary of Interventions described as Occupational Therapy**

Study	Intervention Mode and Content	Theory Base	Duration	Fidelity	Effectiveness
1	Group and individual. Free choice of activities	Psychosocial approach, no theory defined	6 months	No Manual. No fidelity testing	d= -1.22 large effect size in favour of intervention  No CEA
2	Individual. Individualised and client centred programme of therapeutic activities, teaching specific skills such as developing a routine	Delphi technique with experts, no theory defined.	12 months	Intervention schedule. Fidelity monitored through supervision and notes audit.	d= -0.15 Small effect size in favour of intervention  No Cost Effectiveness Analysis(CEA)
3	Individual. Selecting, grading, adaptation and sequencing of activities Adaptation of the social and physical environment. Training and development of skills	Person-Environment-Occupational-Performance Model	12 months	No manual No fidelity testing	Statistically significant improvement in five areas of Social Functioning Scale  CEA: intervention increased cost but comparable to similar services.

Quality rating for studies, 2 and 3, were Strong. However the information required to answer five of the rating questions for study three was not available in the study report, indicating that the study is poorly reported and does not follow Consort statement for reporting RCTs (Schulz et al., 2010). A large effect size in favour of the intervention was reported in Study 1, however this result needs to be interpreted cautious due to the small sample size of 18, and Weak quality rating. Only study 3 reported on the cost of the intervention. The study did not include a formal method of economic evaluation, but reported that the cost of the intervention was

comparable to similar services. The interventions identified as Occupational Therapy exhibit a high level of heterogeneity regarding quality of intervention, format of intervention, outcome measures used, population and effectiveness therefore the results cannot be pooled.

#### *Category 2: Life Skills*

Two interventions were described as life skills. Table 4.5 outlines a summary of the interventions and results of the studies.

**Table 4.5 Summary of interventions described as life skills**

Study	Intervention Mode and Content	Theory Base	Duration	Fidelity	Effectiveness
4	Group format: Independent living Skills: Basic conversation Recreation for leisure	No theory defined	6 months	Manualised intervention  Fidelity tested by observational checklist  Fidelity maintained by feedback from checklist	*d= 0.52 Medium effect size in favour of intervention  No CEA
5	Individual Life Skills Training: Activity scheduling, modelling, shaping and reinforcement.	Model of Functional deficits developed by author	4 months	Manualised Intervention.  Fortnightly supervision to monitor and maintain fidelity to the manual.	*d=0.13 Small effect size in favour of intervention  No CEA

\*Effect size calculated by researcher.

The quality of Study 4 was rated moderate. The study did not report on baseline characteristics of participants, therefore assessment of differences between groups at baseline were not reported. The intervention in this study used a manualised intervention, addressed treatment fidelity in the form of maintenance and assessment and has an adequate sample size to detect effect size. The results of the study can therefore be interpreted reliably. Both studies used different outcome measures, both measures were self-rated. Neither study reported any economic evaluation of the intervention, or referred to it in a separate publication. Both studies had a theoretical basis for the intervention, used manualised interventions and used methods to maintain fidelity to the intervention. The studies described as life skills exhibit heterogeneity with regards to format of the intervention, and outcome measures.

### *Category 3: Role Development*

Study 6 was described as role development.

#### **Summary of the study**

The intervention mode was individual and group format and was eight weeks in duration. It consisted of development of occupational roles and skill acquisition in leisure and using public transport. The targeted areas of occupational performance were using public transport and using leisure facilities. The theory base of the intervention was Role Acquisition Frame of Reference (Cronin Mosey, 1986), a frame of reference developed in the 1970s and last published in 1986. The frames of reference has not been tested or developed since that time.

The intervention was manualised and treatment fidelity maintained through weekly supervision. This cohort study was given a quality rating of moderate, with blinding identified as a weakness because the assessors were aware of the allocated status of the participants. Additionally, the study participants were aware of the research question. No economic evaluation was carried out in this study. The results of the three outcome measures were: Task Skills Scale ( $p=.05$ ), Interpersonal Skills Scale ( $p=.04$ ) and Role Functioning Scale ( $p=.008$ ), indicating a statistical significant change in scores following the intervention. The results need to be interpreted with caution due to the small sample size of 10.

### *Category 4: Meal Preparation*

Four studies were described as meal preparation. A summary of the studies can be found in Table 4.6



**Table 4.6 Summary of Interventions described as meal preparation**

Study	Intervention Mode and Content	Theory Base	Duration	Fidelity	Effectiveness
7	Individual Format: Improving grocery shopping skills by providing strategies to organise and simplify the task and environment.	Acquisitional Frame of Reference (Cronin Mosey, 1986)	Nine sessions	Intervention not manualised  No fidelity monitoring or assessment	d= .59 for accuracy, medium effect size  d= .42 for efficiency, medium effect size  d=.09 for time, small effect size. No CEA
8	Individual format: Learning to cook in home environment: Use of cooking guidelines	No theory defined	Six weeks	Guidelines for cooking use by participants  No fidelity monitoring or assessment	d=0.4 small effect size in favour of intervention  No CEA
9	Format not specified. Food skills programme	No theory defined	Sixteen sessions	Intervention not manualised  No fidelity monitoring or assessment	All 3 participants increased food skills in 2 or more areas.  No CEA
10	Group format: Meal preparation using skill acquisition and psycho-educational approach	Acquisitional Frame of Reference (Cronin Mosey, 1986)	12 weeks	Protocol for each session.  No fidelity monitoring or assessment	No difference in improvement between groups.  No CEA

Three studies (7, 8 and 10) were given a quality rating of Weak. None of the interventions were manualised or fidelity to planned intervention assessed. Heterogeneity was found between all four studies regarding intervention and outcome measures. Three of the interventions demonstrated effectiveness; although, reliability of these results must be taken cautiously due to lack of fidelity assessment.

#### *Category 5: Integration of tasks with cognitive ability*

Study 11 was described as the integration of tasks with cognitive ability.

### **Summary of the Intervention**

The study does not report on the format of the intervention. This study used The Allen Diagnostic Module as the intervention. This module is based on Allen's Cognitive Disabilities Model. This module is an administration manual for a 35 task-based performance assessments. The intervention in the study therefore used the tasks from the manual in each intervention session. The Cognitive Disabilities Model was developed in the 1960s, and no recent developments or testing of the model have been found in relation to adult mental health since then. The intervention consisted of tasks carried out chosen by the level of cognitive ability of the persons and the task is changed according to change in cognitive functioning. The service user has a choice of six tasks to choose from per cognitive level. The duration of the intervention was two months. The intervention was not manualised and no fidelity monitoring or assessments were carried out. This quasi experimental study was given a quality rating of weak. The areas of weakness were blinding and data collection methods. No economic evaluation was completed in this study.

The results of the study found a large effect size in favour of intervention (Cohen  $=1.18$ ). The intervention group improved significantly in comparison to the control group. However the lack of intervention manual and fidelity assessment, in addition to the small sample size ( $n=18$ ), indicates that the results should be interpreted with caution.

### **4.5.4 Narrative Synthesis Stage Three: synthesis of the findings across all intervention categories**

#### *Heterogeneity of studies*

The variation in Standardised Mean Difference attributable to heterogeneity was calculated for the four RCT studies to establish if meta-analysis was appropriate. This resulted in a result of 78.3%, indicating a high level of statistical heterogeneity between the four studies. An I-squared higher than 50% is deemed to be large enough to question whether combining studies is valid (Higgins & Thompson, 2002).

#### *Outcome measures*

Three of the 11 studies have used the same outcome measure, six of the studies used an observer-rated outcome measure, five studies used participant rated outcome measures and two studies used observer-rated and self-rated measures. This indicates a lack of agreement regarding measurement of occupational performance.

#### *Treatment Fidelity*

Three studies (2, 3 and 4) monitored and assessed fidelity to experimental treatment. This was done through regular supervision for all studies and for one study (Liberman et al., 1998)

additionally through weekly observational ratings, which were feedback to maintain high levels of fidelity. No studies reported monitoring or assessment of fidelity to control intervention.

#### *Summary of Effectiveness of interventions*

Seven of the studies reported quantitative data sufficient to calculate the effect size of the interventions. The effect sizes outlined in Section 4.5.3, with the exception of study 4, need to be interpreted with caution, as it is acknowledged that results of studies with small sample size may overestimate effect sizes (Ellis, 2010). For study 10, no inferential statistical data was available regarding effectiveness of the intervention. As previously outlined, the studies vary in intervention focus, population, outcome measures and demonstrate risks of bias, therefore pooling of the effect sizes was not appropriate.

Only one intervention a life skills intervention, used in Study 4, can reliably interpreted as showing effectiveness and can be recommended for use in clinical practice.

#### *Quality of reporting*

Three of the eleven studies were rated Strong for quality. The quality of the reporting of the studies with weak and moderate ratings in this review, affected the ability to accurately appraise the methods used and therefore the results.

Reporting guidelines are available for reporting studies using a several methodologies. Consolidated Standards of Reporting Trials (CONSORT) provide standards to ensure effective reporting of RCT studies (Schulz et al., 2010). To support effective reporting of quasi experimental studies, Transparent Reporting of Evaluations with Nonrandomized Designs (Trend) provides standards (Des Jarlais, Lyles & Crepaz, 2004). Reporting standards have also been developed for reporting qualitative studies also (Tong, Sainsbury & Craig, 2007). It is evident that established reporting guidelines are not routinely used in occupational performance research.

## **4.6 Discussion**

All studies showed the interventions had a positive effect on improving occupational performance, although, not all results were statistically significant. Only one study reported on the clinical significance of the results. Clinical meaning of changes following an intervention for people with a long-term diagnosis is an important area to report in studies to confirm the results are meaningful. Future studies of interventions to improve occupational performance would benefit from reporting on this by reporting clinically significant change.

The results of the review found that a range of specific interventions to improve occupational performance have been studied. Interventions focused on improving specific areas of occupational performance, such as food skills, or on improving a range of areas of occupational

performance, for example life skills. Many interventions had an established theoretical basis, but the theories have not been further developed and the models not tested in mental health. One intervention was not based on any established theoretical basis.

No agreed nomenclature or classification of occupations exists, and a range of classifications can be found in the literature. The classification of occupations into leisure, self-care and work is frequently cited in Occupational Therapy literature. However, these categories overlap and are subjective (Hammell, 2009). Therefore the classification is problematic for research use. The International Classification of Functioning, Disability and Health (WHO, 2001) has been acknowledged as offering a framework for occupation. However, many areas included in the Activity and Participation section are not occupations including for example, Handling responsibility and Making decisions which are not occupations but are instead components of occupational performance. The occupational therapy literature has also described occupational performance at different levels, such as, a group of occupations carried out on a regular basis which together form a daily routine.

The literature review in chapter 2 identified problems of occupational performance for people with a diagnosed psychotic disorder. The main areas of occupational performance found to be problematic were planning and participating in leisure occupations, basic self-care tasks, establishing a daily routine and being able to spend time in a local community. This review found interventions to address meal preparation, which can be considered an aspect of self-care. No specific interventions were found to address personal hygiene an aspect of self-care identified in the literature. The review also found no specific interventions to improve planning and participating in leisure, although, some interventions did address this as part of service users' goals (studies 5, 6 and 7). Additionally, no specific interventions were found to establish a routine of occupations, although one study did incorporate this as part of the intervention (study 2).

The interventions varied in the degree to which they were based on theory or evidence based, indicating the need for interventions to have a clear theoretical basis to ensure thorough evaluation of effectiveness.

Nine different outcome measures were used in the eleven studies, indicating a lack of clarity regarding best tool to use to measure occupational performance. All four RCT studies used different outcome measurement tools further indicating a lack of consensus on the measurement of occupational performance. Cook (2009) indicated that the Social Functioning Scale, which was also used in Studies 3 and 5, was not sensitive enough to detect changes in occupational performance for this client group, reporting a ceiling effect in change scores in the study.

The review identified eleven interventions that were studied; ten interventions require further investigation to demonstrate effectiveness. The results of study 4 indicate the intervention demonstrates reliable evidence of effectiveness and warrants further investigation in a UK setting.

The review has identified a knowledge gap regarding relevant tools to measure occupational performance effectively. For the interventions to be evaluated in adequately powered trials, a relevant outcome measure needs to be developed, or existing outcome measures tested more extensively.

As stated in Section 4.2, interventions to improve occupational performance are currently not in the NICE guidance for schizophrenia, the small sample sizes and lack of consensus regarding outcome measures are current barriers to these interventions being included in the guidance.

No studies were found of interventions specifically focusing on the areas of need following discharge from hospital. The studies found relating to the problems of occupational performance outlined in Chapter 2, did not demonstrate evidence of effectiveness in RCT studies and the interventions did not have rigorous theoretical basis. Therefore none of the interventions found are suitable for use in the pilot study.

#### *Strengths and Limitations*

The strengths of this review are its inclusion of a broad range of types of study to identify as many intervention studies as possible. The synthesis of the characteristics of the interventions studied is also a strength of the study, as this provides a comprehensive review of what interventions have been studied, which is beneficial information for researchers and clinicians.

A limitation of the review is that the results reflect the search terms used to find studies, which may have been insufficiently sensitive. The test search indicated that there is no uniformity of keywords used to describe interventions and areas of occupational performance, resulting in a large number of search terms being used. Despite this effort at comprehensiveness, some studies may not have been found due to the limits of search terms.

## **4.7 Summary and conclusion**

The eleven studies included in the review assessed a range of different interventions and used a range of outcome measures. The results of the studies demonstrated positive improvement in occupational performance. The uniformly positive results may indicate bias, for example, publication bias. Over all this review identified the need for:

- a. an empirically defensible taxonomy of occupational interventions

- b. consensus on standardised outcome measures for use in trials, allowing meta-analytic aggregation.
- c. more theory based interventions
- d. more RCTs with a higher methodological quality (shown by greater use of relevant reporting guidelines and adequately powered) to increase the robustness of the evidence base.

#### *Implication for future research*

There is a need for a systematic approach to the development of interventions that are based on theory and have a clear mode of action of the intervention. The MRC Framework can support this development and the piloting of the intervention. Further research is needed to identify or develop a robust measure of occupational performance.

#### *Implication for current study*

No studies of interventions that focused specifically on improving occupational performance following discharge from hospital were identified in this review. The findings regarding intervention types and outcome measure used will inform the development of a new intervention by highlighting what outcome measures were used to measure occupational performance and how reliable the measures did that.

Since the completion of this systematic review (January 2011) and the development of the intervention, further studies of interventions to improve the occupational performance of people with a diagnosed psychotic disorder have been published. These will be discussed in Section 10.4.

# Chapter 5 Identifying the Theory Base for Intervention

## 5.1 Introduction

This chapter presents sub-study four, the final sub-study aimed at informing the development of the intervention. The aim of this chapter is to identify an appropriate theory to guide a new intervention to improve occupational performance for people with a diagnosed psychotic disorder. Theory has been defined as:

“a network of explanations that label and describe phenomena and propositions that specify relationships between concepts.”

(Kielhofner, 2002, p.4)

The MRC Framework outlines that a good theoretical understanding is needed of how a complex intervention causes change to provide a clear rationale for the intervention (Medical Research Council, 2008). A theoretical basis for a complex intervention is also important in explaining how intervention components interrelate and how they relate to surrogate or final health outcomes. This is important so that weak links in the causal change can be identified during the piloting stage and the intervention amended accordingly. The role of theory within a complex intervention is therefore to explain the process by which the clinical intervention brings about change in the individual. The framework also suggests drawing on existing evidence and theory as well as expertise in the relevant disciplines to identify the most appropriate for the intervention.

The definition of occupational performance, given in Section 1.3, contains several components. Chapter 2 identified the problems of occupational performance for people with a diagnosed psychotic disorder from the literature and Chapter 3 outlined the problems of occupational performance following discharge from hospital. The main problems identified were in the areas of information processing, disruption to skill development, low interaction with local environment, establishing a daily routine of self-care and accessing leisure. Theory relating to occupational performance will need to be applicable to all the problems identified. The most appropriate theory to underpin the intervention will also need to address and explain how changes in occupational performance take place for people with a diagnosed psychotic disorder.

## 5.2 Theoretical knowledge regarding occupational performance

As outlined in Chapter 2 describing the problems of occupational performance for people with a diagnosed psychotic disorder, Occupational Therapists have carried out qualitative studies seeking to understand occupational performance for people with a diagnosed psychotic disorder. Additionally, ten of the eleven interventions identified in Chapter 4 were carried out solely by Occupational Therapists. Therefore the most comprehensive theory relating to occupational performance is likely to be found in occupational therapy literature. Occupational

Therapists are an appropriate profession to carry out the intervention developed as part of this study. This has an impact on the theory choice, as the theory will need to be acceptable to the Occupational Therapists implementing the intervention.

There is a long history of the practice of occupational therapy with individuals with a diagnosed psychotic disorder dating back to the beginnings of the profession in the early 1900s (Barker Shwartz, 1998). The profession has built up theoretical approaches, models and assessment tools relating to mental health over time with each OT implementing them in their unique way which has led to a lack of clarity about OTs' core roles and specialist skills.

In 2000, the Medical Research Council published a framework for the development and evaluation of randomised controlled trials for complex interventions to improve health in response to the increasing need for evidence based clinical interventions (Medical Research Council, 2000). In 2003 the College of Occupational Therapists, identified the MRC framework as a useful mechanism to describe occupational therapy practice and commissioned a study to identify the parameters and elements of occupational therapy practice in the UK (College of Occupational Therapists, 2003). The study developed a contemporary definition of occupational therapy and a model of the complex content of occupational therapy practice. The study used the theoretical and modelling phases of the 2000 MRC's framework to outline the components of occupational therapy practice and the relationships between these components. The study involved a review of recent occupational therapy literature and a UK wide consultation with OTs in clinical practice. The 2000 MRC framework outlines that the first step in evaluating a complex intervention is 'to explore relevant theory to ensure the best choice of intervention' followed by the next step to 'identify the components of the intervention and the underlying mechanisms by which they will influence outcomes'. However, the framework does not define theory clearly and states a formal theory or informal evidence may be used to establish the theoretical basis on the intervention (Medical Research Council, 2000). The framework gives a brief hypothetical example of a complex intervention, a physiotherapy intervention for knee injury, to outline the various potential components of the intervention. Another example of a complex intervention it briefly outlines is the intervention of a stroke unit. Additionally the framework provides only four pages of guidance regarding the theoretical and modelling phases in relation to methodological issues. Given the newness of the document at the time, published examples of the application of the framework were not available. Therefore detailed application of the framework to developing a clinical intervention is not given which may hinder the implementation of the document.

The results of the study commissioned by the College of Occupational Therapists outlined the occupational therapy process including assessment, case formulation, goal setting, action planning, action, ongoing assessment and revision of action and outcome measurement in relation to occupation. The action component of the intervention consists of a one page brief



description of the actions the OT would carry out during the intervention, for example, analysis, selection, adaption, grading and sequencing of an activity. The results also included factors that the occupational therapist brings to the therapeutic situation and a description of the external influences on the occupational therapy process. It was anticipated that the definition of occupational therapy and the specification of the components of occupational therapy intervention could be used to research occupational therapy and to develop national occupational therapy indicators. Creek and colleagues (2005) published a paper expanding on the concept of OT as a complex intervention by further outlining the concept of complexity.

The document and paper created debate within the profession regarding the nature of occupational therapy practice and defining the practice of occupational therapy as a complex intervention. In 2007 Duncan and colleagues argue that complex interventions have been confused with complex systems in defining occupational therapy as a complex intervention and argues that this leads to inaccurate claims regarding occupational therapy practice (Duncan, Paley & Eva, 2007). One example that Duncan and colleagues disagree with is the claim that Creek and colleagues make in stating that the outcomes of occupational therapy are unpredictable and that the active ingredients cannot be separated out. Duncan and colleagues argue that it may be difficult, but not impossible, to separate out active ingredients and that by stating it is not possible indicates that systematic research into the effectiveness of occupational therapy interventions is not possible.

Following the paper by Duncan and colleagues, Lambert and colleagues further debated the concept of defining occupational therapy as a complex intervention, arguing that the term complex adaptive systems may better describe how occupational therapy has been defined in the document (Lambert et al., 2007). This opinion piece also disagrees with the statement made by Creek (2005) that there can be no standardised interventions in occupational therapy and responded by stating that in an evidence-based practice health care environment "this appears to be a dangerous position to take".

In 2009 a five year review of the impact of the document was published (Creek, 2009). Despite the arguments outlined in the above published opinion pieces in addition to the publication of revised guidance from the Medical Research Council regarding developing and evaluating complex interventions (Medical Research Council, 2008), Creek reviews the impact the document has had on the profession of occupational therapy without critique of the document itself, or responding to the comments published regarding defining occupational therapy as a complex intervention. Creek does not suggest how the document could be further developed or updated. Furthermore a letter to the editor links the need to critique the document with the need to explain the findings of the review that the document had not had an impact on research (Kolehmainen, 2009).

The defining occupational therapy as a complex intervention document has influenced the profession by describing the domain, values and beliefs and processes of occupational therapy practice, and by initiating the debate regarding how to define OT interventions. At the time of its publication it provided a contemporary description of occupational therapy practice based on available guidance at the time on developing a complex intervention. Currently the application of the defining occupational therapy as a complex intervention document is not suitable for use in developing an occupational therapy intervention for three reasons.

Firstly, at the time of publishing the "*Occupational therapy defined as a complex intervention*" document, it was agreed that the document would be valid for five years, after which time it would no longer represent the most up-to-date thinking regarding occupational therapy practice (Creek, 2009). Therefore the document is not intended to be used beyond 2008 as it does not represent current occupational therapy practice. Secondly, since its publication the new guidance from MRC regarding developing and evaluating complex interventions, has been published in 2008, this updates the MRC framework used to develop the "*Occupational therapy defined as a complex intervention*" document (MRC, 2008). The 2008 framework reflects more recent understanding regarding complex interventions and is therefore more appropriate for use in developing an intervention than the 2000 framework. Specifically the 2008 framework is more appropriate for use as it emphasises that identification of the active ingredients in an intervention is vital in evaluating and optimising their effectiveness. The new guidance puts greater emphasis and clarity on identifying a theoretical understanding of how the intervention causes change, and use of an appropriate model to do this (Medical Research Council, 2008). The greater emphasis on identifying the active ingredients of an intervention to increase its effectiveness is in agreement with the criticism of the definition of occupational therapy outlined by Lambert and colleagues and Duncan and colleagues. Additionally Kolehmainen (2009) also states that the techniques used by OTs need to be specified and replicated in order to build up the evidence. Therefore the 2008 framework in addition to statements by Lambert and colleagues, Duncan and colleagues and Kolehmainen indicate the further development of a clearer understanding of interventions to improve health, and how to evaluate complex interventions since the publication of "*Occupational therapy defined as a complex intervention*".

Thirdly, there is an increasing emphasis on seeking to gain an in-depth understanding of identified clinical problems and developing interventions targeted at these specific clinical problems. As a profession occupational therapy has further developed, as can be seen from the interventions identified in the systematic review in Chapter 4, to acknowledge that clinicians implement interventions targeted at specific problems and that these specific interventions need to be described and researched in addition to identifying clear a theoretical rationale. Therefore whilst the publication "*Occupational therapy defined as a complex intervention*" describes the parameters of occupational therapy practice, it is not detailed enough to be suitable for use in developing an occupational therapy intervention for a specific clinical situation. For example an

occupational therapy intervention following discharge from hospital, where the focus is on identifying the most appropriate techniques and theory to support the process of change caused by the intervention and targeted at specific areas of occupational performance that have been identified as important at this stage of the care pathway.

Therefore whilst the document "*Occupational therapy defined as a complex intervention*" has made an important contribution to the occupational therapy profession, it has not been used in this study to guide the development of an intervention to increase occupational performance following discharge from hospital. As outlined in Chapter 1, the MRC framework for developing and evaluating complex interventions to guide the study.

As outlined in 5.1 this chapter aims to identify an appropriate theory to guide a new intervention to improve occupational performance for people with a diagnosed psychotic disorder. Occupational therapists use applied theory in clinical practice often in the form of conceptual models of practice. Models of practice provide a theoretical basis for practice by providing explanations about the process and practice of the profession (Duncan, 2006).

The Researcher Development Framework has identified that an important component of a successful researcher is their knowledge of the area of study (Vitae, 2011). Additionally, much has been written about the influence of the world view of the researcher and multiple identities that a researcher may hold (Finlay & Gough, 2003). Consideration needs to be given to the position of the researcher, specifically in this study, to the knowledge of the researcher.

The researcher is an Occupational Therapist who has been in clinical practice as a Head OT in acute adult mental health for six years prior to carrying out this research. My area of interest within research has originated in my role as a clinical OT in adult mental health services. I have knowledge and experience of use of theory and models in clinical practice. Specifically, having previously worked as a clinician working in acute mental health services, I am familiar with the practice of occupational therapy in this area and the models of practice used. The team of OTs that I worked within used the Model of Human Occupation (MOHO) as the model of practice. This means that I have an understanding of and have experience of using MOHO in clinical practice. MOHO has been an important clinical tool in assessing strengths and areas for development of occupational performance of people with mental health problems. This has highlighted to me the importance of using a model of practice to guide clinical assessment and intervention. Despite my experience and knowledge of occupational therapy practice and the relevant models of practice used in mental health by OTs, as a researcher I have been mindful of the bias this may bring in developing a new intervention for use by occupational therapists. I have drawn on that knowledge but remained curious as a researcher about other sources of theory and knowledge regarding occupational performance following discharge from hospital.

As a researcher I am aware of the need to be rigorous in examining available theory and that other models of practice exist other than MOHO.

### **5.3 Identification of theories of occupational performance for use with intervention**

Despite the researcher's knowledge and experience of using MOHO in clinical practice and the acknowledgement of wide use of MOHO in clinical practice, the evaluation of other models of practice focusing on occupational therapy were searched for to ensure a rigorous approach was used to identify relevant theory.

The following criteria for an appropriate theory need to be met:

- Focus on describing the process of change in occupational performance
- Demonstrates construct validity
- Assessment tools based on the model
- Suitable for application with people with mental health problems

To identify relevant theory a search of the literature was carried out using four sources:

1. An online search of CINAHL and Medline databases. The search terms used were theory, theoretical knowledge, theory-practice relationship, theoretical AND occupational therap\* OR activities of daily living OR leisure.
2. Online book catalogues of King's College London and College of Occupational Therapists, were searched.
3. A hand search of mental health and occupational therapy text books at the College of Occupational Therapists library.
4. Reference lists of the papers found in Chapter 2 and Chapter 4 were hand-searched to identify additional published papers relating to theoretical knowledge of occupational performance.

### **5.4 Results**

The search found eight theoretical models of practice that had evidence of use in mental health clinical settings. The models are summarised and evaluated against the pre-defined criteria in Table 5.1.

**Table 5.1 Summary of Models of Practice**

<b>Model</b>	<b>The process of change in occupational performance</b>	<b>Construct validity</b>	<b>Application to mental health clinical practice</b>	<b>Assessment tools associated with the model</b>
Activities Therapy Model	Outlines seven developmental adaptive skills. Illness or disability can impact on functioning of these skills. Change is demonstrated through the learning of adaptive sub-skills.	No studies found	Examples of use in group settings with adults with mental health problems (Duncan, 2006)	Four assessments: Evaluation Questionnaire Behaviour Survey Group Interaction Skills Scale Group Interaction Assessment Form
Canadian Model of Occupational Performance and Engagement (CMOP-E)	Outlines the dynamic relationship between person, occupation and environment to produce occupational performance and engagement. Change in one area impacts on all other components.	No studies found	Examples of use in community setting with individuals with mental health problems	Canadian Occupational Performance Measure
Cognitive Disability Model	Outlines the relationship between an individual's cognitive abilities and the activity abilities. Cognitive changes are on a continuum alongside a person's ability to function.	No studies found	Study of model in outpatient adults with diagnosis of schizophrenia (Raweh & Katz, 1999)	The Allen Cognitive Level Screen The Routine Task Inventory The Cognitive Performance Test
Kawa Model	An optimal state of well-being in one's life is metaphorically portrayed by an image of a strong, deep, unimpeded flowing river. Aspects of the environment and personal circumstances, like certain structures found in a river, can influence that flow. Changes take place by increasing flow by focusing on problem solving and positive opportunities.	No studies found	Case studies of use of model with adults with mental health problems (Duncan, 2006)	None

Model of Human Occupation (MOHO)	Consists of four main constructs: Volition (personal causation, values and interests), habituation (habits and roles), performance (performance capacity), and environment. MOHO states changes in one domain can impact on other domains.	Studies found that test or expand the theory have been published.(Barrett, Beer & Kielhofner, 1999; Helfrich, Kielhofner & Mattingly, 1994; Neville-Jan, 1994; Parkinson et al., 2008)	Evidence of its use in mental health clinical settings to design services and intervention programmes (Ásmundsdóttir, 2009; Lee et al., 2011; Turner & Lydon, 2008)	14 assessments in total assessing occupational performance, performance skills, performance patterns, context and activity demands
Occupational Adaptation	Focuses on improving a person's adaptive skills to carry out tasks. Change occurs when the desire for mastery, when the person intends to produce a response to the occupational challenge that will be adaptive and therefore will lead to mastery.	No studies found	Published case studies of use of model with people with mental health problems (Adami & Evetts, 2012)	Relative Mastery Measurement Scale
Occupational Performance Model (OPM)	Focuses on eight constructs: occupational performance, occupational role, occupational areas, and occupational performance components, core elements of occupational performance, environment, space and time.	Model constructs developed by reviewing literature and clinical practice, and testing model.	Studies found of use of model with people with psychosis.	The Perceive, Recall, Plan and Perform System of Task Analysis Comparative Analyses of Performance (CAPs)
Person Environment Occupational Performance Model (PEOP)	Focuses on the person and relevant intrinsic factors and extrinsic factors that influence performance of occupations.	No studies found	One study found of use of model in mental health intervention study (Cook & Howe, 2003)	Activity card sort (ACS) Kitchen task assessment (KTA)

## **5.5 Discussion**

The identified models varied in the extent to which they met all the criteria. Two of the eight models had evidence of construct validity. All models relate to occupational performance, but some focus on one specific component. The individual constructs are adaptive skills (Activities Therapy Model and Occupational Adaptation), levels of motivation for occupation (Model of Creative Ability) or cognitive functioning (Cognitive Disability Model). Eight of the models include the relationship between the person and the environment. This level of agreement indicates the importance of the environment in occupational performance. The importance of the environment was also identified in the literature in Chapter 2 and the service user and staff focus groups in Chapter 3.

All eight models of practice had evidence for use in mental health clinical practice. However, the Model of Human Occupation (MOHO) had evidence for use at the service model level as well as clinical intervention level within clinical practice. Additionally, MOHO is used as a model for the mental health care packages tool in use within local NHS trusts (Lee et al., 2011).

MOHO outlines the relationship between a person's motives for occupation, habits and roles, and physical and cognitive performance capacities in the context of their environment. These components are in agreement with the problems of occupational performance for people with a diagnosed psychotic disorder, identified in Chapter 2 and 3. These problems were information processing, disruption to skill development, low interaction with local environment, establishing a daily routine of self-care and accessing leisure. This indicates that MOHO provides a good theoretical basis on which to understand the problems of occupational performance for people with a diagnosed psychotic disorder. Additionally, MOHO has the largest number of clinical assessment tools. These are useful in monitoring changes in each domain, thus outlining the process by which an intervention works.

The Model of Human Occupation was selected as the theoretical model to guide the intervention to improve occupational performance following discharge from hospital for people with a diagnosed psychotic disorder.

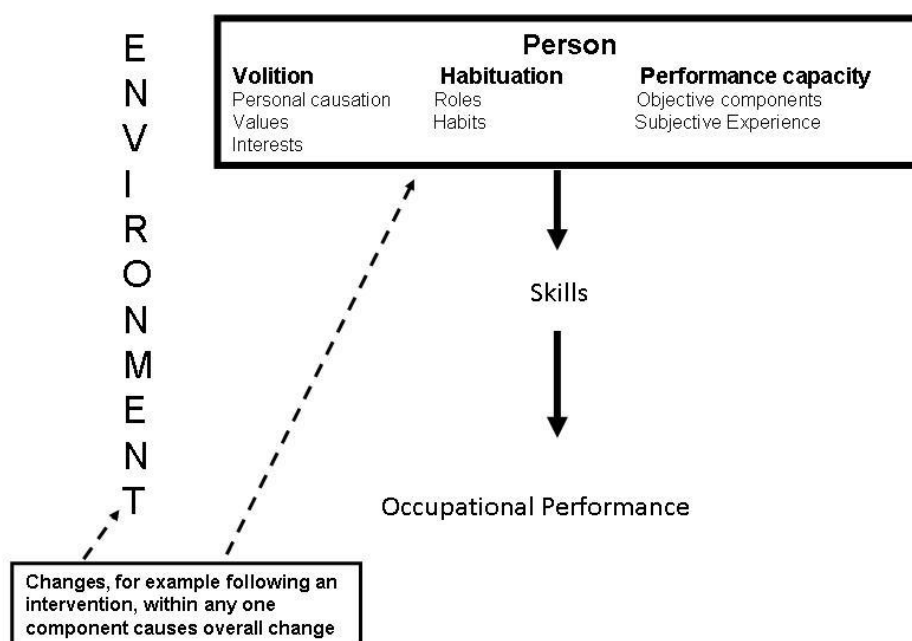
### **5.5.1 Summary of Process of Change within Model of Human Occupation**

MOHO consists of four main constructs, the first three of which are internal to the person, whilst the fourth construct relates to the external environment:

- Volition (personal causation, values and interests)
- Habituation (habits and roles)
- Performance capacity
- Environment.

The model is a heterarchical system (Kielhofner, 2008), meaning that each component contributes something equally to a dynamic system. Additionally, consideration of any aspect of a person's volition, habituation and performance capacity also takes into consideration how the environment influences the person. The three internal components are maintained and changed through what a person does, what the person thinks and what the person feels about doing. In clinical practice the model is used to understand a person's occupational performance by examining the person's volition, habituation and performance capacity and their environment. Intervention aims to change components within the system to improve occupational performance. Figure 5.1 outlines the mechanism of change within MOHO.

**Figure 5.1 Mechanism of change within Model of Human Occupation**



From Table 5.1 we can see that MOHO has been studied with regards to testing the components of the model (Barrett et al, 1999; Helfrich et al, 1994; Neville-Jan, 1994; Parkinson et al., 2008). This indicates that the components of the model all have validity regarding their role and function within the model. In clinical practice this means the OTs will have a clear, consistent and evidence-based approach to framing and improving occupational performance. The model is used in clinical practice currently in both NHS trusts taking part in the study and therefore the OTs currently use MOHO in practice. This will support the OTs to integrate the newly developed intervention into their existing knowledge of occupational performance based on MOHO.



As identified from the literature review in Chapter 2 a range of factors affect a person's occupational performance. These include internal factors such as self-efficacy and motivation in addition to external factors such as accommodation and the person's social and physical environment. The focus groups with service users and staff in Chapter 3 also identified internal factors including service users' reluctance to be more independent and building a picture of the future whilst on the ward. The focus groups additionally identified external barriers such as the person's social and physical environment.

As can be seen from figure 5.1 the Model of Human Occupation consists of four components: volition (motivation for occupation), habituation, performance skills and the person's environment and that a change in any of these components can impact on all the other components. The heterarchical nature of the components emphasises that all the components contribute something different to the model and that all the components work together. The components of the model and their relationships therefore match the areas impacting on occupational performance as outlined in Chapter 2 and 3, indicating that MOHO is an appropriate model of practice on which to base the intervention being developed and as the mechanism of change occupational performance.

## **5.6 Therapeutic relationship model**

In addition to the Model of Human Occupation, the model through which change in occupational performance occurs during the intervention, the importance of the therapeutic relationship regarding implementing interventions to improve occupational performance was highlighted in Chapter 3. The relationship between clinician and service user is acknowledged to be an important factor in determining positive therapy outcomes. Therefore an awareness and understanding of therapeutic use of self is an important element to support positive outcomes of the intervention. An important component of the intervention is the inclusion of a theoretical approach to the therapeutic relationship during the intervention sessions. To outline the process of the therapeutic relationship throughout the intervention, The Intentional Relationship Model (Taylor, 2008) is used alongside the model of occupational performance identified. The model is intended to complement existing theoretical frameworks of clinical practice, as it focuses only on the therapeutic use of self in the context of clinical practice. The Intentional Relationship Model is not a model of practice therefore, but a model to support the OTs to focus attention on their therapeutic relationship with the service users throughout the intervention. This will support the use of MOHO to guide the intervention and will ensure that the intervention is implemented as intended.

The model outlines therapeutic modes which are specific ways of relating deliberately and thoughtfully to a client within a therapeutic interaction. It outlines six therapeutic modes, which are advocating, empathising, collaborating, encouraging, problem-solving, and instructing. The OT may change their therapeutic mode depending on the response of the service users or the

situation encountered. The therapeutic modes will be used to during the intervention to guide the therapeutic approach used by the clinician during the intervention.

The intervention being developed was specifically designed to be implemented following discharge from an acute inpatient ward. The OTs must therefore develop a therapeutic relationship with the service user that will support a gradual return or development of self-care and leisure occupations. For example, when a service user has just been discharged from hospital they may feel unsure of the tasks required of them, the OT may need to use an instructive approach to ensure the service user can meet their basic self-care needs. The OT could use the instructive mode to suggest actions to take, for example, to buy some food. In the weeks following discharge the OT may use the instructive mode less often but increase their use of a collaborative mode to ensure the service user can be fully involved in decision making as the service user adjusts to living more independently in the community.

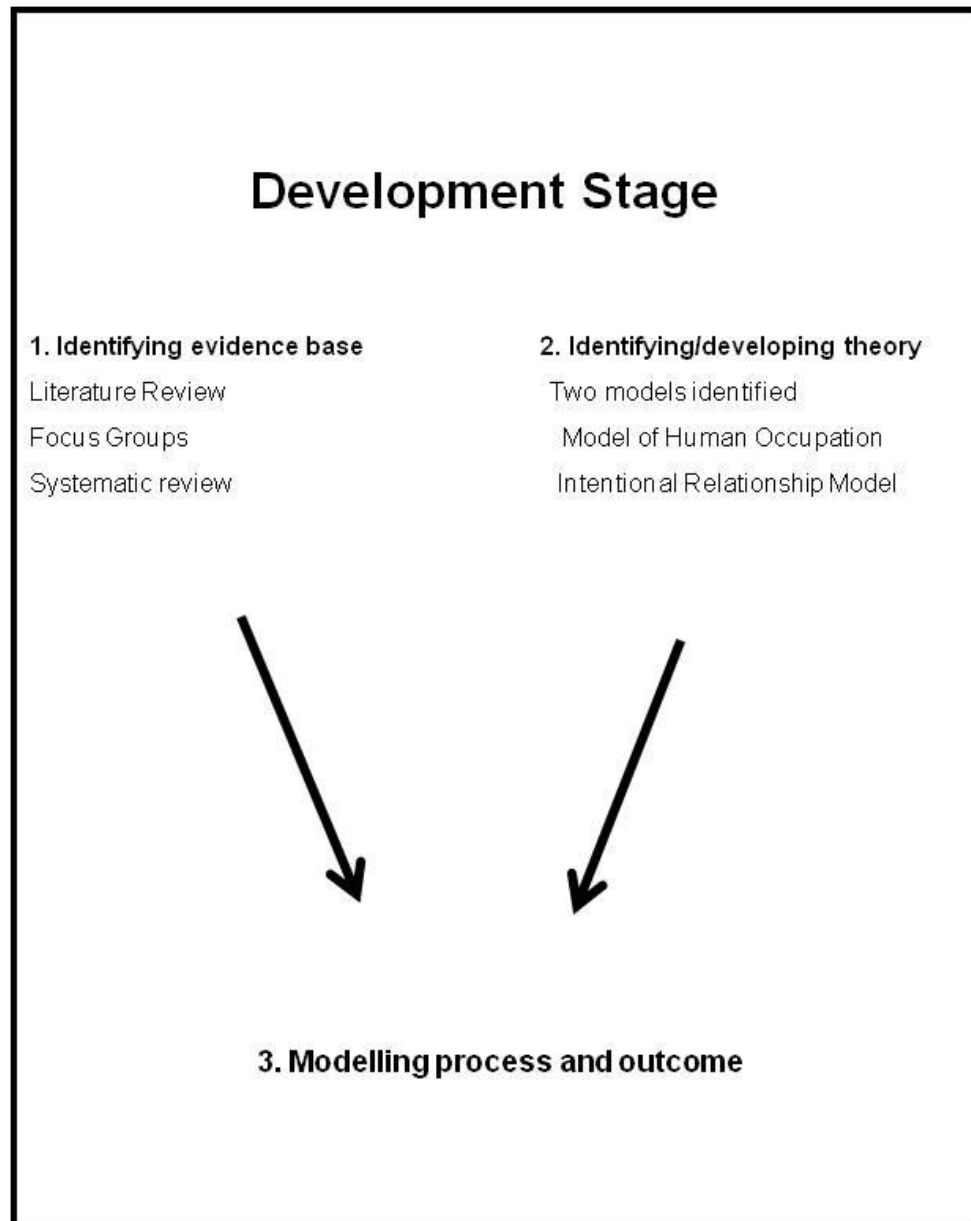
Chapter 6 details the process of development of the intervention and will model the process of change for the intervention based on the Model of Human Occupation. Chapter 6 will also outline the role of the Intentional Relationship Model within the intervention.

# Chapter 6 Development of Intervention

## 6.1 Introduction

The aim of this chapter was to describe the process of developing an intervention to improve occupational performance for people with a diagnosed psychotic disorder, following discharge from hospital. This involves developing the intervention on the basis of evidence reported in Chapters 2 to 5, modelling the intended change process, manualising the intervention and development of a fidelity scale. Figure 1.1 outlined the process of developing and piloting an intervention following the MRC framework. The development stage can be found in Figure 6.1.

**Figure 6.1 Development of the intervention following the MRC framework**



Chapters 2-5 contain four sub-studies to identify and synthesise evidence to inform the intervention. The sub studies comprised:

1. A literature review regarding identified problems of occupational performance for people with a diagnosed psychotic disorder (Chapter 2),
2. Focus groups with clinical staff and people with a diagnosed psychotic disorder who have recently left hospital (Chapter 3),

3. A systematic review of interventions to improve occupational performance following discharge from hospital (Chapter 4)
4. A literature review regarding the theory relating to occupational performance (Chapter 5). These four sources of evidence are now used to develop the intervention.

## 6.2 Development of the intervention

Five steps were involved in the development of the intervention:

1. Synthesising the findings of sub-studies
2. Modelling process and outcome
3. Developing the intervention manual
4. Maximising treatment fidelity

### 6.2.1 Synthesis of the findings of the sub-studies

Table 6.1 summarises the findings of the sub-studies and the implication for the content, structure and format of the intervention.

**Table 6.1 Summary of findings of studies and implication for intervention**

Sub-study	Finding	Implication for intervention
Literature review of psychosis and OP	Problems with cognitive functioning, performance skills and knowledge, process skills	Intervention to Include: Assessment of volition, habituation and performance.
		Activity Grading
	Gender difference	These findings to be discussed during the training regarding implementing GLOW, to raise the clinicians' awareness of gender differences, whilst remaining client centred.
	Internal factors	Intervention to Include: Assessment of volition, habituation and performance.
		Developing self knowledge of OP to continue working towards long term goals post intervention.
	Social and physical environmental barriers	Assessment of home environment using REIS-SF
		Environmental enhancements and considerations
	Meaningful Occupations	Identification of meaning of occupations and service user led goal setting
	Routine	Assessment of routine included in the intervention
		Activity Grading
	No problems specific to post discharge have been identified.	Study needed to identify new information regarding OP following discharge from hospital

Sub-study	Finding	Implication for intervention
Focus Groups	Slowly picking up daily life again	Intervention to be provided for four months
		Intervention to Include: Activity grading
	Importance of therapeutic use of self	Intentional Relationship Model
	Balancing a focus between basic self-care and long term goals	Stepped level of intensity to support basic self-care post discharge followed by longer term goals regarding leisure
		Developing self knowledge of OP to continue working towards long term goals post intervention.
	Building a picture of the future whilst on the ward	Start intervention prior to discharge from hospital
	Reluctance to be more independent	Use of MOHO to improve motivation for occupation, and occupational performance
		Assessment of OP using MOHOST, REIS-SF and UK Interest Checklist
		development of self knowledge and self management of own OP
	Barriers to accessing leisure activities	Assessment of OP included in the intervention
		Intervention to take place in relevant community venue
		Use of Interest Checklist
	Managing meals	Use of strategies to overcome physical barriers in home environment
		Use of activity grading as a component
Systematic review	No intervention found to improve OP following discharge from hospital	Development of a new intervention
Literature review of theory of OP	Evidence based theoretical model regarding OP found in OT literature	Intervention implemented by OTs Intervention based on Model of Human Occupation

The intervention will be based on two models, Model of Human Occupation and the Intentional Relationship Model, and will use a stepped intensity approach with four components, as described in Section 5.5.

### **6.3 Description of the components**

The intervention is called Graduating Living skills Outside the Ward (GLOW) and consists of four components.

#### **Component 1: Assessment of volition, habituation and performance capacity**

This involves clinical assessment to understand the current and past performance capacities and goals of the individual. Three clinical assessment tools will be used by the Occupational Therapists. The assessment tools are:

MOHOST (Model of Human Occupation Screening Tool)

REIS-SF (Residential Environment Impact Scale- Short Form)

UK Modified Interest Checklist.

MOHOST is an observational assessment tool of volition, habituation, performance and the person's environment. These four areas are the components of the MOHO and therefore enable the researcher to monitor the process of change by assessing if change takes place in the four components of MOHO, as outlined in the model of the intervention. Psychometric testing has confirmed construct validity, reliability and validity for use with adults with mental health problems (Burns et al., 1993; Goodman et al., 1993).

REIS-SF is an observational assessment tool of a person's home environment under the following categories: physical space, resources, social support, and opportunities for occupational performance (Parkinson, Fisher & Fisher, 2011).

UK Modified Interest Checklist is a self-report of the service users' strength of interest and engagement in 74 activities in the past, present and future. Interests are listed in nine categories that focus on different types of activity choices (Heasman & Salhotra, 2008).

#### **Component 2: Activity grading**

This is an intervention technique that is recognised as a core intervention used by Occupational Therapists to improve occupational performance (Hersch et al., 2004). Activity grading consists of balancing the ability of the person with the task, to ensure the person can gradually complete the task independently over time. During the first four weeks of the intervention, the clinician will carry out the task with the service user, for example, food shopping, and provide verbal prompting of the stages of the task. It is expected that by week five the service user can carry out the task independently, or with planned support as arranged between the clinician and service user.

#### **Component 3: Environmental enhancements and considerations**

The environment can be defined as the particular physical and social, cultural, economic, and political features of one's context that impact upon the motivation, organization, and

performance of occupation (Kielhofner, 2008). As this definition implies, several dimensions of the environment may affect an individual's occupational life. Moreover, most operate in a variety of contexts (e.g. home or neighbourhood). Within these contexts, people encounter different physical spaces, objects, people, expectations, and opportunities to do things. It is important to note the difference between features of an environment and its actual influence on each individual.

Environmental impact refers to the opportunity, support, demand, and constraint that the environment has on a particular individual. Whether and how environmental opportunities, resources, demands, and constraints are noticed or felt depends on each person's values, interests, personal causation, roles, habits and performance capacities.

The intervention consists of strategies as outlined by Kielhofner (2008):

1. Strategies to overcome physical environmental barriers in home environment

Negotiate possibilities for changing space and objects

Identify the physical space required for the successful completion of occupational forms/tasks

Introduce new items of interest in the home environment (pictures, radio)

Introduce new items to prompt occupational performance in home environment (calendar, diary, kitchen equipment.)

Support client to commit to habit training around altered space and new objects (morning routine, weekly routine of washing, cleaning)

2. Strategies to overcome social environmental barriers

Re-examine old social groups and occupational forms/tasks

Explore new social groups and occupational forms/tasks

Discrimination and other negative attitudes are reduced through finding social environments that support occupational performance with reduced discrimination present, for example, identifying a suitable shop to buy food etc, suitable routes to shops and leisure facilities

Advise client about available support networks

Identify people in social environment who can support occupational performance.

**Component 4: Developing self knowledge of occupational performance**

This component consists of sharing knowledge and explaining occupation in relation to mental health. Occupational Therapists hold knowledge and skills regarding occupation and occupational performance that can be imparted to service users to enable them to use this knowledge in their own lives beyond the duration of the intervention. The clinician will carry out the assessments in conjunction with the service user and explain the elements of the



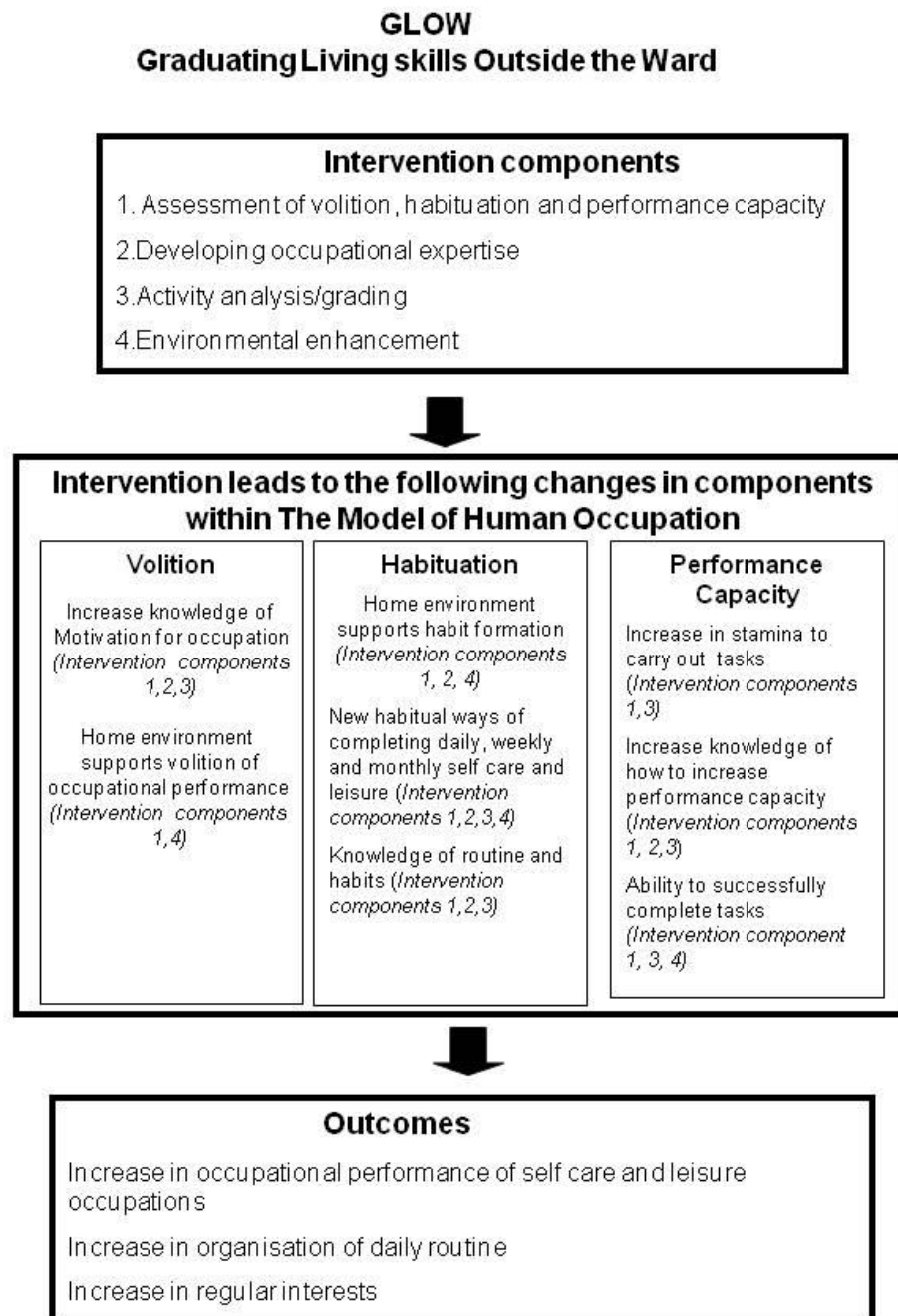
assessments throughout. The clinician will share their clinical understanding of the service user's occupational performance with the service user.

## **6.4 Modelling process and outcome**

The MRC Framework outlines the importance of modelling a complex intervention, prior to a full scale evaluation. The framework provides two case studies regarding the modelling process. The case studies outline a causal modelling approach to developing a theory-based intervention and an economic modelling approach to developing a complex intervention (Eldridge et al., 2005; Hardeman et al., 2005). This indicates that there are several ways to model an intervention, and the framework does not provide criteria for choosing a modelling approach and the qualities of a theory used within a modelling approach.

A causal modelling approach was used in this study to outline the events taking place as part of the intervention and the expected change occurring leading to the main outcome. Figure 6.2 outlines the GLOW model showing the intended impact of the GLOW intervention on the person and their environment and how these impacts result in improvement of occupational performance of self-care and leisure.

**Figure 6.2 Model of intervention**



## 6.5 Developing the intervention manual

Manuals provide structure for an intervention's delivery, enable the intervention to be consistently delivered by different therapists, facilitate clinician training, and allow treatment replication in different contexts (McMurran & Duggan, 2005). Additionally, to ensure treatment fidelity to an intervention, manualisation of an intervention is recommended (Carroll & Nuro,

2002). Currently, intervention manuals are not widely used in occupational therapy clinical practice. Manuals developed as structured protocols for evaluation studies, such as pilot or RCT studies, are less commonly available to practitioners, in part due to the paucity of research in the area of occupational performance (Blanche et al., 2011). Therefore consideration of the issues concerning manualisation of occupationally focused interventions is required to ensure the manual is acceptable to clinicians for use with service users. A challenge in the manualisation of an intervention is in providing sufficient structure and consistency while maintaining the potential for individualisation that characterises occupational therapy practice (Blanche et al., 2011).

The intervention manual was developed following guidance regarding a stage model of development of a clinical treatment manual (Carroll & Nuro, 2002). The guidance refers to psychotherapy manuals but has been used as the structure of the current manual as the model is relevant to manualisation of interventions to improve occupational performance. The model of manual development proposes a stage development of the manual in parallel to the stages of research of a new intervention. The model presents three stages of manual development for use in: pilot/feasibility, efficacy and effectiveness trials. The purpose of stage one manual development is to provide an initial specification of the treatment techniques, goals, and theoretical active ingredients. This stage is in parallel to a pilot or feasibility study of the intervention contained in the manual, and so was used here.

The stage model outlines that a pilot or feasibility study intervention manual should contain the following sections:

- Overview, description and rationale
- Conception of the disorder or problem
- Treatment goals
- Contrast to other approaches
- Specification of defining interventions
- Session content
- General Format

These areas were included in the manual.

### **6.5.1 Summary of intervention manual**

#### *Duration of Intervention*

The optimum duration of the intervention has been identified as four months, based on the progress of picking up daily life following discharge from hospital as outlined by the service users in the focus groups.

Four weeks high intensity phase (Week 1 to 4)

Assessment using MOHOST, REIS-SF and Interest Checklist, weekly visits, plus a weekly phone call to focus on self-care and home environment. Instructing, encouraging and advocating are the three therapeutic modes used.

Six weeks medium intensity phase (week 5- 10)

Fortnightly meetings, with final two meetings in community venues relevant to O.P. goals. Problem solving, collaborating and encouraging are the three therapeutic modes used.

Six weeks low intensity phase (week 11-16)

Fortnightly meetings in home and community venue to re-assess using MOHOST, REIS-SF and interest checklist, support self-management techniques to sustain OP achievements. Collaborative, problem solving and encouraging are the three therapeutic modes used.

The completed intervention manual was emailed to 6 clinicians and the facilitator of the focus groups, who had experience of using services and being admitted to hospital, for comments on all aspects of the intervention. The panel were also asked to suggest names for the intervention. Three OTs and the service user provided comments on the intervention. The clinicians' comments questioned how realistic the frequency of visits and duration of high intensity phase was, given existing workloads.

Two changes were made to the intervention following the consultation, the reduction of the high intensity phase from six to four weeks, and the reduction of frequency of visits from twice weekly visits to weekly visits and a phone call during the high intensity phase. GLOW (Graduating Living skills Outside the Ward) was the name chosen for the intervention, by the panel member with experience of using services. The developed manual can be found in Appendix 9.

### **6.5.2 Treatment Fidelity**

Treatment fidelity refers to strategies used to monitor and enhance the reliability and validity of an intervention (Bellg et al., 2004). Furthermore it refers to the procedures used to ensure that testing of an intervention is carried out in a reliable and valid manner. The process of manualising an intervention is an important step in ensuring treatment fidelity. Best practice regarding enhancing treatment fidelity has been outlined by the National Institute of Health (NIH) Behaviour Change Consortium (Bellg et al., 2004). The authors highlight the importance of treatment fidelity in pilot studies of new interventions to ascertain whether the outcomes were due to the intervention being implemented as intended or due to other factors that were added or omitted. Additionally the authors identify that by reducing random and unintended variability in the study through optimizing treatment fidelity, statistical power can be improved. This in turn can reduce costs of future studies of effectiveness of the intervention.

Approaches to enhancing treatment fidelity have been identified in relation to five areas: study design, training providers, delivery of the treatment, receipt of the intervention and enactment of treatment skills (Carroll & Nuro, 2002). These strategies informed the implementation approaches used in this study. Specifically:

1. The content and rationale for the intervention were outlined in the manual.
2. All participating clinicians received standardised training regarding implementing GLOW, by one trainer (the researcher). This aimed to minimise variation in training experiences from different trainers.
3. Clinician skill acquisition was ensured through active discussion of the role and definition of each component of the intervention.

Assessing treatment fidelity is a key component of a pilot study. At the end of the intervention schedule a semi-structured interview with the clinicians was carried out to ascertain the extent to which they adhered to each component of the intervention. Where non-adherence to components occurred the clinicians were asked to expand on reasons for this. The service user participants were also asked questions at the end of the intervention regarding the intervention they received.

# Chapter 7 Measuring occupational performance

## 7.1 Introduction

This chapter aims to identify a suitable outcome measure for use as the primary measure in the pilot study of the GLOW intervention. The systematic review of interventions in Chapter 4 identified that there is no agreed valid and reliable outcome measure of occupational performance. This chapter aims to identify and appraise published measures of occupational performance relevant for use with people with a diagnosed psychotic disorder with regard to the areas of self-care and leisure.

## 7.2 Measurement of occupational performance

The definition of occupational performance used in this study is:

“choosing, organizing and carrying out an occupation in interaction with the environment”

(Creek, 2010, p.89)

Therefore measurement of occupational performance needs to include a measurement of a person's ability to not only carry out an occupation, but also to choose and organize the occupation. This multi-dimensional nature of occupation means that a single measure may not capture all aspects of occupational performance.

The GLOW intervention targeted occupational performance of self-care and leisure. Therefore the outcome to be assessed is changes in actual doing of occupations. The intervention focuses on self-care tasks: personal and domestic, and community and home leisure activities. Therefore the primary outcome measure will need to reflect these domains. Another important change expected for service users following the intervention is an increase in daily routine of self-care and an increase in leisure occupations. Therefore a secondary outcome measure is required to measure these, if the primary measure does not include this domain alongside self-care and leisure.

### 7.2.1 Terminology

Occupational performance has been conceptualised in several ways, for example, a recent compendium of psychosocial measures (Johnson, 210) use categories of functional assessment, community living, social functioning and global functioning. The third edition of Mental Health Outcome Measures, (Thornicroft & Tansella, 2010) separates functional outcome measures into those assessing global functioning those assessing social disabilities. Aspects of occupational performance are measured within both groups. The difference in categorisation

used in outcome compendia further confirms the lack of consensus regarding classification of occupations.

### **7.2.2 Methods of collecting data**

There are several ways of collecting data to measure occupational performance. Approaches include self-report, carer report, observational measurement methods and standardised performance based measures. Whilst occupational performance is an observable phenomenon, the individual's perspective of their own occupational performance is important. A self-report measure, however, relies on the person providing an accurate report of their abilities. There may be several sources of bias. A person may lack self confidence and under-estimate their ability to carry out self-care or leisure occupations. Social desirability bias may occur when the person answers in a way that they think will please the person administering the assessment.

Observational measurement is also prone to bias. Reliable data from observational measures is dependent on the environment in which the measurement is taking place and the skills of the researcher to interpret the person's ability. Standardised performance measurements are also impacted on by the assessment environment, which may affect occupational performance and involve tasks which differ from their natural settings.

The process of identifying appropriate measures will now be presents by reviewing and evaluating self-report measures of occupational performance.

## **7.3 Identifying the occupational performance measure**

The following sources were used to search for Outcome measures:

1. Outcome measures used in studies included in the systematic review reported in Chapter 4
2. Search for reviews of measures in mental health
3. Reviewing key text books of outcome measurement in mental health
4. Expert consultation with researchers in the field of outcome measurement in mental health and in the field of occupational therapy

The main criteria for selecting the outcome measure were that the instrument measures performance of self-care and leisure occupations, and is designed for use with adults with a diagnosed psychotic disorder. Additionally the outcome measure was required to be of relevance and be used across mental health settings and disciplines to ensure the results all studies could be pooled in future systematic reviews to compare effectiveness of interventions.

## **7.4 Results**

Five controlled studies were found in the systematic review. Five different outcome measures were used in these studies to measure occupational performance. These were Independent

Living Skills Survey, Performance assessment of Self-Care Skills (PASS), Allen Cognitive Screen (ACLS-90), Scale for Interactive Observation in occupational therapy (EOITO) and Social Functioning Scale.

Two Reviews of measures were found, one of social functioning measures and one of measures of functional recovery. A Review of social functioning measures,(Burns & Patrick, 2007) identified most frequently used social functioning measures scales in randomised controlled trials of antipsychotics. The three most frequently reported measures were the Global assessment of functioning scale (GAF), the Global Assessment Scale (GAS) and the Social Functioning Scale (SFS).

A Review of Instruments for Measuring Functional Recovery (Duncan, Paley & Eva, 2007) identified six scales

UPSA (UCSD Performance-Based Skills Assessment)

UPSA, Brief (Brief UCSD Performance-Based Skills Assessment)

SSPA (Social Skills Performance Assessment)

MMAA (Medication Management Ability Assessment)

TABS (Test of Adaptive Behaviour in Schizophrenia)

ILSS-SR: Independent Living Skills Survey—Self-Report form

GAF: Global Assessment of Functioning

ILS: Independent Living Scales

The review concluded that no gold standard measure exists, and that all measures need further testing. The review identified that the most utilized and valid measure of functioning is the UPSA.

A Compendium of Psychosocial Measures (Johnson, 210) identified measures in several categories relevant to occupational performance. The categories were Functional Assessment, Community Living, Social Functioning and Global Functioning. Of the measures included in Functional Assessment category, only one measure was identified as containing measurement items appropriate to measure occupational performance, The Independent Living Skills Survey. The Social Functioning category included three measures that contained measurement items relevant to measuring occupational performance, the Social Functioning Scale, Social and Occupational Functioning Assessment Scale (SOFAS) and UPSA. The Global Functioning category contained GAF and GAS.

In consultation with experts in the field of outcome measurement of OP in mental health, other intervention studies of occupational performance in adults have used AMPS (Fossey et al., 2006; Haslam et al., 2010; McNulty & Fisher, 2001; Moore, Merritt & Doble, 2010). This is an observational assessment that is used to measure the quality of a person's activities of daily



living, however it requires a calibrated administrator and is time consuming to use. Table 7.1 presents a summary of the measures reviewed that most closely met the inclusion criteria.

**Table 7.1 Summary of measures identified**

<b>Measure</b>	<b>Rater</b>	<b>Domains of occupational performance covered</b>
Independent Living Skills Survey ILSS	Self reported	Appearance and Clothes Personal hygiene Care of personal possessions Food preparation/Storage Health Maintenance Transportation Leisure and community Job seeking Job
UPSA	Observation of Role play	Household chores, Communication, finance, transportation, planning recreational activities
Global Assessment of Functioning (GAF)	Researcher rated	Psychological, social and occupational functioning
Global Assessment Scale (GAS)	Researcher rated	Earlier version of GAF
Test of Adaptive Behaviour in Schizophrenia;	Researcher rated	Performance based measure
Social Functioning Scale	Researcher rated	Social engagement/ Withdrawal, Interpersonal behaviour Pro-social activities, recreation, independence- competence Independence- performance Employment/ occupation

## 7.5 Selected measures

Following examination of the components of the measures in Table 7.1, the Independent Living Skills Survey- Self Report (ILSS-SR) was selected as the primary measure. The domains of the measure closely match the focus of the intervention, that is, personal care and domestic activities of daily living, and leisure occupations at home and in community.

The self report version of this measure (Wallace et al., 2000) was chosen as the primary outcome of the pilot study.

### 7.5.1 Psychometric Properties of ILSS-SR

Reliability Coefficient alpha scores for the nine subscale items ranged from 0.67 to 0.84. This score range indicates acceptable internal consistency. Split-half reliabilities alpha scores ranged from 0.63 to 0.89, indicating acceptable internal consistency (Wallace et al., 2000).

Inter-rater reliability was tested between respondents on ILSS-SR and carers /family responses on ILSS-I (Informants version), results ranged from  $r = 0.21$ -  $0.59$ , indicating low levels of agreement as could be expected between self report and relative/carer report.

Validity coefficients for The ILSS-SR with Global Assessment Scale (GAS) were  $r = 0.38$ , and-  $0.32$  with Brief Psychiatric Rating Scale (BPRS). The low correlation with these measures indicates the ILSS-SR is measuring different constructs as expected (Wallace et al., 2000).

#### Sensitivity to change

Testing of this indicated that the measure is a sensitive measure of functional living skills when used with people with severe and persistent mental illness. Ceiling effect of the measure may occur when used with less severe mental illness.(Wallace et al., 2000).

#### Scoring of measure

The self report version of the ILSS, consists of 70 items grouped into 10 areas: personal hygiene (12 items), appearance and care of clothes (9 items), care of personal possessions (6 items), Food Preparation/Storage (7 items), Health Maintenance (7 items), Money Management (5 items), Transportation (5 items) and Leisure and Community (12 items). The questions are rated by the participant by providing one of three answer options: "Yes or "No", or "Not Apply". The answers are summed and averaged per area. Items answered "Not Apply" are ignored. An area is not scored if three or fewer items are answered with other than "Not Apply".

The measure was developed in the United States of America, and therefore some of the items were not relevant to UK population. A UK version of the measure has not been developed. The measure therefore required amending prior to use in this study. The wording of two of the Food Preparation/Storage items were changed to relevant UK equivalent words. That is, candy, soda and groceries were changed to sweets, fizzy drinks and food shopping.

The phrasings of two of the Transportation items were also changed: California Driver's licence was changed to UK drivers licence, and the word subway was removed from list of public transport in question two.

One of the Health Maintenance questions refers to health insurance, such as Medicaid, which is not of relevance to UK population. This question was therefore removed from the measure. Additionally, the Money Management category, containing five questions, was omitted, as four

of the five questions are not of relevance to the UK population included in the study. Therefore the measure used consisted of nine items instead of ten.

A disadvantage of this outcome measure is that it does not have normative data with which to calculate clinical significant changes in scores. ILSS-SR does not measure changes in routine or interest in the occupation. No outcome measure was identified that measure this.

In summary this chapter identified the primary outcome measure for the study. The ILSS-SR was selected as the items of measurement in the scale best reflected the aims of the intervention. Chapter 8 presents the methods for piloting the developed intervention, GLOW.

# Chapter 8 Methods for Piloting the Intervention

## 8.1 Introduction

Subsequent to the development of the GLOW intervention following guidance as outlined by the MRC framework, 2008, the next stage of the framework is the feasibility/piloting stage. The MRC Framework emphasises the importance of carrying out a pilot study to test procedures ahead of a definitive evaluation of the intervention. This chapter describes the method for the pilot study, and Chapter 9 gives the Results.

## 8.2 Study design for evaluation studies

The choice of study design used to evaluate a new intervention depends on the research question and the context of the study. The aim of this study is to evaluate the effectiveness of the intervention, so an experimental study design is appropriate. The most robust method of evaluating an intervention is a randomised controlled trial. An RCT reduces bias, by ensuring the two groups are balanced with respect to factors, including those we do not know about, which may influence outcome. The ultimate aim therefore of randomisation is to ensure that the study groups only differ with respect to the treatments each group has received. This means we can attribute any difference between the study groups to the treatment they have received.

Randomisation may not always be possible for a number of reasons, for example, costs or resource limitations. Quasi experimental study designs can be considered in that instance; however this design does have disadvantages of not controlling for confounding variables. Confounding variables are those factors that are not the focus of the study and can affect results as they influence the independent variables being tested. Several quasi experimental design types exist, including one-group pre-test post-test design, case control design and an interrupted time-series design.

A randomised controlled design was planned for use in this study, but was not possible due to the limitations of number of cases each OT could implement GLOW with, and locality based structure to clinical services. The intervention was designed to commence within two weeks of discharge, therefore a block randomisation was not possible as this method would require more than one participant to be recruited within two weeks, which may not have been possible for each locality.

A non-randomised controlled design was used in this study and was chosen over other quasi experimental designs for a number of reasons. An interrupted time-series design was not possible as the intervention was designed for use following discharge from hospital. Recruiting and collecting baseline data using this study design would therefore have been at a time when the service users was not ready for discharge and may have been still in the acute phase of

illness. The service users may therefore be unable to consent or be well enough to answer questions required for assessment. A case control design was discounted due to the difficulty of matching participants in control and intervention group on specific factors which would limit who could enter the study and hence reduce recruitment.

Evaluations of complex interventions can be undermined by problems of acceptability and delivery of the intervention or recruitment and retention (Bower, Wilson & Mathers, 2007; Prescott et al., 1999). A pilot study can therefore lead to changes in study design and provide justification for future randomised controlled trial (Lancaster, Dodd & Williamson, 2004). A literature review of use of pilot studies identified seven objectives of a pilot study (Lancaster et al., 2004). The identified objectives are: sample size calculation, integrity of study protocol, testing of data forms or questionnaires, randomisation procedure, recruitment and consent, acceptability of intervention, and selection of most appropriate primary outcome measure.

Process evaluation has also been identified as an important component of a pilot study of a complex intervention (Medical Research Council, 2008). Process evaluation aims to assess how the intervention was implemented by distinguishing between the components of the intervention and investigating contextual components that affect the intervention. Process evaluation can help to distinguish between interventions that are inherently faulty and those that are badly implemented (Das et al., 2011). Five commonly used elements of process evaluation have been identified: fidelity, dose, reach, recruitment and context (Saunders, Evans & Joshi, 2005). Four of these elements, fidelity, dose, recruitment and context, have been used in the process evaluation of the study. Reach, which examines the proportion of the priority target audience who participated in the intervention, was not used in the study. Fidelity has been defined as the extent to which the intervention was implemented as planned and is consistent with the underlying theory and philosophy (Saunders et al., 2005).

Dose, contains two components, dose delivered and dose received. Dose delivered is defined as the extent to which all of the intended units or components of the intervention were provided. They define dose received as the extent to which participants engaged in the intervention and how they reacted to specific aspect of the intervention. Recruitment is defined as assessing what planned and actual recruitment procedures were used, and also assessing the barriers to recruitment and continued involvement in the study. Context assesses what factors in the organisation, community, social/political context or other situational issues could potentially affect either intervention implementation or outcomes.

This study evaluated the effectiveness of the GLOW intervention. However, the results concerning effectiveness of the intervention must be interpreted as preliminary and cannot be interpreted as reliable. This is due to the small numbers of participants and the associated likelihood of type I error (i.e. a false positive finding). However, outcome data from a pilot study

of a new intervention is essential in order to perform a sample size calculation for a larger trial (Lancaster et al., 2004).

### **8.2.1 Outcome measurement Considerations**

As outlined in Section 7.5, The ILSS- SR was chosen as candidate outcome measure.

Studies of complex interventions often report statistical significant changes in measures, but neglect to report the clinical meaning of the change in score. Inferential statistics can be used to infer change but this may not translate into a valid and meaningful difference experienced by the treatment recipient. For example, a small change on a symptom rating scale may be statistically significant in a study with a large sample, but the clinical importance of such a change may be negligible.

For interventions to improve occupational performance to be widely implemented in clinical practice and be funded by commissioners, they must demonstrate that the changes the interventions lead to are clinically meaningful. Methods of measuring clinically significant change have been developed within rehabilitation and psychological areas of research. Two methods were identified and considered for use in this study, Reliable Change Index (Jacobson & Truax, 1991) and Potential Improvement (Heinemann et al., 1987; Shah, Vanclay & Cooper, 1990).

Jacobson and Truax (1991) proposed the Reliable Change Index (RCI). Reliable change is that which is unlikely to have arisen from just fluctuation caused by an imprecise measurement tool. Clinically significant change is sufficient improvement to have moved the client to a score more representative of the general population than a clinical population. Therefore, scores on the measure are required for a clinical and non-clinical population to establish cut-off point for clinical significance. It is calculated by the following formula:  $RC = \frac{\text{pre-test score} - \text{post-test score}}{\text{standard error of the difference between the two test scores}}$ .

Achievement of Potential Improvement is an alternative metric calculated as (actual improvement divided by potential improvement, where potential improvement is maximum score minus baseline score. The score is multiplied by 100 to present a percentage of potential improvement (Heinemann et al., 1987; Shah et al., 1990).

Calculation of percentage of potential improvement was used in this study to assess clinically significant change. In addition to this method, an assessment of change to service user participants' routine and interest regarding occupational performance was carried out at baseline and end point to assess the impact of the intervention on daily life. No suitable valid and reliable measures were identified to assess this.

Therefore two categories of the Occupational Circumstances Assessment Interview Rating Scale (OCAIRS) were used to record changes in habits and interests (Forsyth et al., 2005). This tool is based on the Model of Human Occupation, the model that the intervention is based on. Therefore the tool will relay findings regarding changes within constructs within the model as well as ensuring construct validity, despite the tool not being numeric and not suitable as a main outcome measure for the study.

#### *Reporting Method*

The pilot study follows reporting guidelines (Des Jarlais et al., 2004), for non-randomised study designs.

### **8.3 Aims and objectives**

The aim of this pilot study was to evaluate the use of an intervention to improve occupational performance of people with a diagnosed psychotic disorder following discharge from an adult acute mental health ward.

The seven objectives of the pilot study were:

Objective 1 (Effectiveness): To provide a preliminary estimate of effectiveness of the GLOW intervention, so as to inform a future power calculation.

Objective 2 (Outcome): To test the appropriateness of ILSS-SR as the primary outcome measure.

Objective 3 (Context): To investigate the contextual factors impacting on delivery of the intervention

Objective 4 (Acceptability): To investigate the acceptability of the intervention to service users and clinicians

Objective 5 (Fidelity): To assess the extent to which the manualised intervention is given

Objective 6 (Dose): To assess the dose delivered and dose received of GLOW

Objective 7 (Recruitment): To assess recruitment rate to the study

### **8.4 Methods**

#### **8.4.1 Design**

A non-randomised controlled study was used to investigate preliminary effectiveness of the intervention. The design consisted of two groups. One group of participants received GLOW intervention and the other group received treatment as usual following discharge from hospital.

#### **8.4.2 Setting**

The study took place in community mental health services in two mental health trusts in South East London: South London and Maudsley NHS Foundation Trust (SLaM) and Oxleas NHS Foundation Trust.

### **8.4.3 Participants**

Service user participants were adults aged between 18 and 65 with a clinical diagnosis of a psychotic disorder using NHS adult mental health services.

Staff participants were Occupational Therapists (OTs) working in community mental health services.

### **8.4.4 Sample size**

The target sample size for the pilot study was 30 service users per intervention arm, as recommended by Lancaster, (2004). This would allow one trial parameter to be estimated, an effect size estimate. This will meet Objective 1 (Effectiveness).

In terms of recruitment rate, it was assumed that 50% of OTs would provide GLOW to one service user and 50% to two service users, giving a target of 20 OTs to be recruited.

### **8.4.5 Inclusion and Exclusion Criteria**

Inclusion Criteria Service Users were:

- in-patients identified by the OT or other staff working on the ward as being due to be discharged within two weeks, or have been discharged within the previous two weeks
- identified by the screening OT as having identified problems with occupational performance post discharge from hospital

Exclusion criteria for service users were:

- Under the care of Home treatment teams
- Under the care of early Intervention services in SLaM (due to the teams being over researched.)
- Substance misuse being main presenting clinical problem.

Inclusion criteria for staff were:

- Occupational Therapists with at least six months experience of working as an Occupational Therapist
- Working within community mental health service in SLaM Psychosis Clinical Academic Group, in or adult mental health services in Oxleas NHS Trust.

Exclusion Criteria for staff:

- Working within home treatment teams.
- Working in early intervention services in SLaM



#### **8.4.6 Measures**

##### **Study outcome measures**

The primary outcome was The Independent Living Skills Survey-Report (ILSS-SR) a 70 item self-report measure of basic functional living skills of individuals with severe and persistent mental illness (Wallace et al., 2000). It assesses 10 functional areas. Appearance and Clothing (9 items), Personal Hygiene (6 items), Care of Personal Possessions (6 items), Food Preparation/Storage (7 items), Health Maintenance (7 items), Money Management (5 items), Transportation (5 items), Leisure and Communities (12 items), job seeking (4 items), job maintenance (3 items). The response to questions are rated by the assessor by scoring each answer, 1= Yes, 0= No. Scoring is done by summing answers and averaged per functional area. The maximum score per area is therefore 1, and the maximum total score on the measure is 10.

To assess change in routine and interests, the OCAIRS was used (Forsyth et al., 2005). The full measure is a non-standardised semi structured interview, consisting of 12 sub-scales assessing occupational performance. The full measure is burdensome and therefore only questions specific to Habits (five questions) and interests (seven questions) were used. Scoring was done by the researcher who categorised the responses to the questions into one of four categories regarding participation in occupation: Facilitates, Allows, Inhibits and Restricts. Facilitates is given a score of four, Allows a score of three, Inhibits a score of two and restricts a score of one.

Socio-demographic characteristics were recorded at baseline for all service user participants. The following details were recorded from the service users' clinical records: Date of birth, ethnicity, Borough of residency, accommodation, duration of use of mental health services, number of admissions and duration of recent admission.

##### *Measures administered as part of the intervention*

The Model of Human Occupation Screening Tool (MOHOST) (Jayaram, Rattehalli & Adams, 2012) was used by the OTs implementing the intervention, during the first four weeks to provide a clinical baseline of occupational performance and to identify areas requiring improvement. MOHOST is based on MOHO, the model that the GLOW intervention is based on. MOHOST is an observational assessment tool for use in clinical practice. It consists of 24 items, organised into six sections: Volition (Motivation for Occupation), habituation (pattern of occupation), Communication and Interaction Skills, Motor skills, process skills and Environment. Each item is rated as to the extent to which the personal or environmental factors support or detract from an individual's participation in occupations. A four-point scale indicates whether the factor facilitates, allows, inhibits, or restricts participation in occupations. The maximum score for the measure is 96. The measurement properties of MOHOST support internal validity,

construct validity and inter-rater reliability and sensitivity to detect change (Burns et al., 1993; Goodman et al., 1993; Kramer et al., 2009; Pan et al., 2011).

The Residential Environmental Impact Scale- Short Form (REIS-SF) (Glynn, 2012) was used by the OTs implementing the intervention. REIS-SF is a non-standardised assessment that provides a structure for gathering and summarising data about the home environment. It assesses the environmental impact of the person's home on their occupational performance. The REIS-SF is also based on MOHO. The scale consists of 17 items organised into four sections, physical space, resources, social support, and opportunities. The four-point scale used in MOHOST is also used in this measure. The maximum score on the measure is 68. It generates recommendations to enhance the qualities of the environment. Reliability and validity of the REIS-SF has not established.

#### *Acceptability and Process Evaluation Questionnaire for Service User Participants*

A questionnaire asking the service users which component of GLOW intervention they received was developed by the researcher. The questionnaire also included questions regarding the acceptability of the intervention. The questionnaire is shown in Appendix 17.

#### *Acceptability and Process Evaluation Questionnaire for Staff Participants*

A questionnaire was developed by the researcher regarding the fidelity of the intervention to the manual, in addition to the acceptability of the intervention. The questionnaire can be found in Appendix 18.

### **8.4.7 Control Group**

Service users participating in the control group received care co-ordination only. Care co-ordination is the standard care that service users currently receive following discharge from hospital. A named qualified mental health worker-the care co-ordinator-carries out a seven day follow-up home visit with the service users. The care co-ordinator completes a care plan with the service user, which contains details of plans to address needs in health, social care, housing, employment, and any financial problems. The care co-ordinator meets the service user regularly to support implementation of these plans and monitor mental health.

### **8.4.8 Intervention Group**

Service users in the intervention group received GLOW. A detailed description of the intervention can be found in Section 6.4.1. In summary, it was provided by Occupational Therapists in community settings to people with a diagnosed psychotic disorder, following discharge from hospital. This intervention consists of a 16-week stepped intensity intervention focused on improving occupational performance of self-care or leisure in the participants' home and local community.

#### **8.4.9 Procedures**

NHS Research Ethics Committee approval for the pilot study was received in October 2011 from the National Research Ethics Service Committee London – East (REC reference: 11/LO/1061), a copy of which can be found in Appendix 11. Research and Development approval was obtained from both NHS Trusts.

##### *Clinician recruitment*

OTs meeting the inclusion criteria for this study were identified by the Lead OT for each service area in both NHS trusts. The identified OTs were invited to participate in the study to pilot the intervention with service users. Potential OT participants were approached by a researcher and Lead OT for adult community mental health services. The potential OT participants were given a Staff Participant Information Sheet, which can be found in Appendix 12, and given the opportunity to discuss the study with the researcher before deciding to take part. The OTs who chose to participate were asked to sign a consent form (shown in Appendix 13). The aim was to recruit a target number of 20 Occupational Therapists.

Once recruited, OTs received four hours of training regarding the GLOW intervention facilitated by the researcher and based on the intervention manual. The training described the underpinning models (Intentional Relationship and Model of Human Occupation), and provided a rationale for their use. The format of the intervention was then explained, including a rationale for using a stepped approach. The training also included a description of the components of the intervention and examples of how they would be used, as well as providing examples of completed assessments used within GLOW. Training was participatory, and involved sharing of experience and expertise from the participants as well as the facilitator.

##### *Service user recruitment*

A screening tool, outlining the inclusion criteria was provided to OT participants, and OTs and other professionals screening service users for the study. The screening tool can be found in Appendix 16.

Three approaches were used to recruit service user participants into the study. The first approach

used when there were OTs working with the ward teams, was that the OTs identified eligible service users who were currently in-patients. The service users were asked by the ward OT or a member of ward team if they would be interested in taking part in the study. Service users expressing an interest in taking part were approached by the researcher, and given Participant Information Sheets, which can be found in Appendix 14, as well as having the opportunity to discuss the study with the researcher before deciding if they wanted to take part.

The second approach was used, in situations where the acute inpatient mental health wards did not have Occupational Therapists within the ward multidisciplinary team (MDT). The researcher recruited service user participants into the study by informing the MDT of the study and providing details of the inclusion criteria for the study. The researcher attended the wards on days where ward rounds occurred to identify and meet potential participants.

The third approach involved the OT participants recruiting service users from within their team. The OTs screened referrals to the team from the wards and screened the teams' service users currently on the ward or recently discharge for eligible participants. The researcher attended the team base to meet interested participants. The researcher went through the Service User Participant Information Sheet, emphasising that involvement is voluntary and consent can be withdrawn at any time. The care co-ordinator for service users agreeing to take part in the study in the intervention group were contacted to inform them of the GLOW study and to ensure the service users was not involved in other research studies which may over-burden the service users. They were then asked to provide written informed consent by signing a consent form. The service users were aware of their allocation status at the point of consenting to the study.

#### *Allocation methods*

The intended method of allocation was to alternate referrals received per locality into intervention and control groups. However, this was not always possible, for example, where the OT had capacity to take on a second service user within the study if the time of the referral was suitable or the service user was on their caseload the service user was put in the intervention group. Therefore, service user participant allocation was done on the basis of the availability of the OTs, with efforts made to balance the arms by gender where possible.

Once informed consent was obtained, clinical and socio-demographic characteristics and baseline ILSS-SR and OCAIRS were administered by the researcher. For intervention group participants only, the OT was then asked to start the GLOW intervention. The participating OTs administered MOHOST, REIS-SF and the Interest Checklist with their allocated participants at the beginning of the intervention schedule. Each OT had the potential to implement GLOW with more than one service user. The service user participants received the GLOW intervention for four months, in their homes and their local community.

At the end of the intervention (four months after baseline), the researcher contacted the service user and organised a face-to-face follow-up meeting. At this meeting, the post-intervention assessments were administered, comprising ILSS-SR, OCAIRS and a questionnaire covering fidelity, dose received and acceptability. The participating OTs administered MOHOST, REIS-SF and the Interest checklist during the last 1-2 sessions of the intervention schedule. Service users received £5 for participating in baseline measures, and £5. for end point assessments. The Acceptability and Process Evaluation Questionnaire was administered to the OTs in the

format of a semi-structured interview to enable them to elaborate on answers to the questionnaire.

Recruitment procedures were recorded and monitored through discussion with each OT. Barriers to recruitment were discussed with the OTs during recruitment phase of study, including any organisational barriers that were encountered. The recruitment processes were recorded by the researcher in the form of a summary of discussion with clinical staff regarding recruitment, and details of participants' reasons for declining to participate. For locations with slower recruitment rates and locations where recruitment of Occupational Therapists or service user participants failed, a record of all emails and a summary of phone call summaries were kept. Frequency of contacts and site visits were recorded.

#### *Context assessment*

The contextual factors that may have an impact on the study were recorded by the researcher as they arose throughout the study in addition to contextual factors arising during the semi structured interviews with staff.

## **8.5 Analysis**

#### *Estimate effectiveness of the intervention*

Baseline clinical and socio-demographic characteristics for each group were compared to identify any differences between groups at baseline. Repeated measures analysis of covariance was applied to examine the intervention effect.

A non-parametric test (Mann-Whitney U Test) was used to test for significant difference between groups on ILLS-SR. Clinical significance in score on ILSS-SR was assessed by using Potential improvement calculation, the method outlined by Shah and colleagues (1990), in addition to use of OCAIRS subscale results to indicate impact of intervention on routine and interest in occupations.

#### *Test appropriateness of primary outcome measure*

Assessment of floor or ceiling effect was completed by calculating the percentage of participants who achieved the lowest possible score and the highest possible score at baseline and end point. Floor or ceiling effects are considered to be present if more than 15% of participants achieved the lowest or highest possible score, respectively (McHorney & Tarlov, 1995). The presence of floor or ceiling effects can indicate that extreme items are missing in the lower or upper end of the scale, indicating limited content validity. As a result, participants with the lowest or highest possible score cannot be distinguished from each other, thus reliability is reduced. Responsiveness is also limited because changes cannot be measured in these participants (Terwee et al., 2007).

*To investigate the acceptability of the intervention*

The data from the acceptability questionnaires within the Service User and Staff Participant Acceptability and Process Evaluation Questionnaires were collated and summarised to identify the extent of acceptability of the intervention to the OTs and the Service users. The data from the semi structured interviews with OT were also used to identify any components of the intervention that were not satisfactory to them in implementation or for the service users to receive.

The semi structured interviews were analysed using thematic analysis to investigate the OTs perspective of implementing the intervention. The steps involved in thematic analysis have been described in Section 3.2.2.

*To assess dose delivered and dose received of the intervention*

The results for each question relating to dose delivered from the Staff Participant Acceptability and Process Evaluation Questionnaires were collected and a percentage dose delivered was calculated for each component of the intervention. The results for each question relating to dose received from the Service User Participant Acceptability and Process Evaluation Questionnaires were collated and the findings summarised.

This chapter has presented a rationale for the methods used in this study. The chapter has presented the objectives, procedures and methods of analysis used in this the study. Chapter 9 outlines the results of the pilot study and process evaluation.

## Chapter 9 Results of Pilot Study

### 9.1 Baseline Results

Eighteen Occupational Therapists were recruited from two NHS trusts. The roles and teams of OT participants are outlined in Table 9.1

**Table 9.1 Team and clinical roles of Occupational Therapists (n=18)**

Role Distribution			
Site	n	Protected OT role %	Care co-ordination role %
SLaM NHS Foundation Trust			
Psychosis Community Service	5	5	95
Placement, Assessment, Monitoring and Support Team	1	100	0
Community OT service	6	100	0
Total	12		
Oxleas NHS Foundation Trust			
Early Intervention	3	40	60
Assertive Community Treatment	1	0	100
Community OT service	2	100	0
Total	6		

The OTs worked in five types of community service, all for adults with a diagnosed psychotic disorder and with specific clinical needs. The Placement, Assessment, Monitoring and Support (PAMS) team is for service users who live in supported accommodation. The Early intervention teams (EIT) in Oxleas NHS Trust are for young people who have experienced a first episode of psychosis. The Assertive Community Treatment team is a community service for adults with a severe and enduring psychotic illness, who find it difficult to engage with services and who are at risk of repeatedly becoming ill and being admitted to hospital. The Community Psychosis teams are for people with a diagnosed psychotic disorder who are on the Care Programme Approach (CPA). CPA is a process of ensuring people with mental health problems receive clinical services in a planned and co-ordinated way (Department of Health, 2008b). Five of the OTs working in Community OT services in SLaM worked within the same team, whose aims

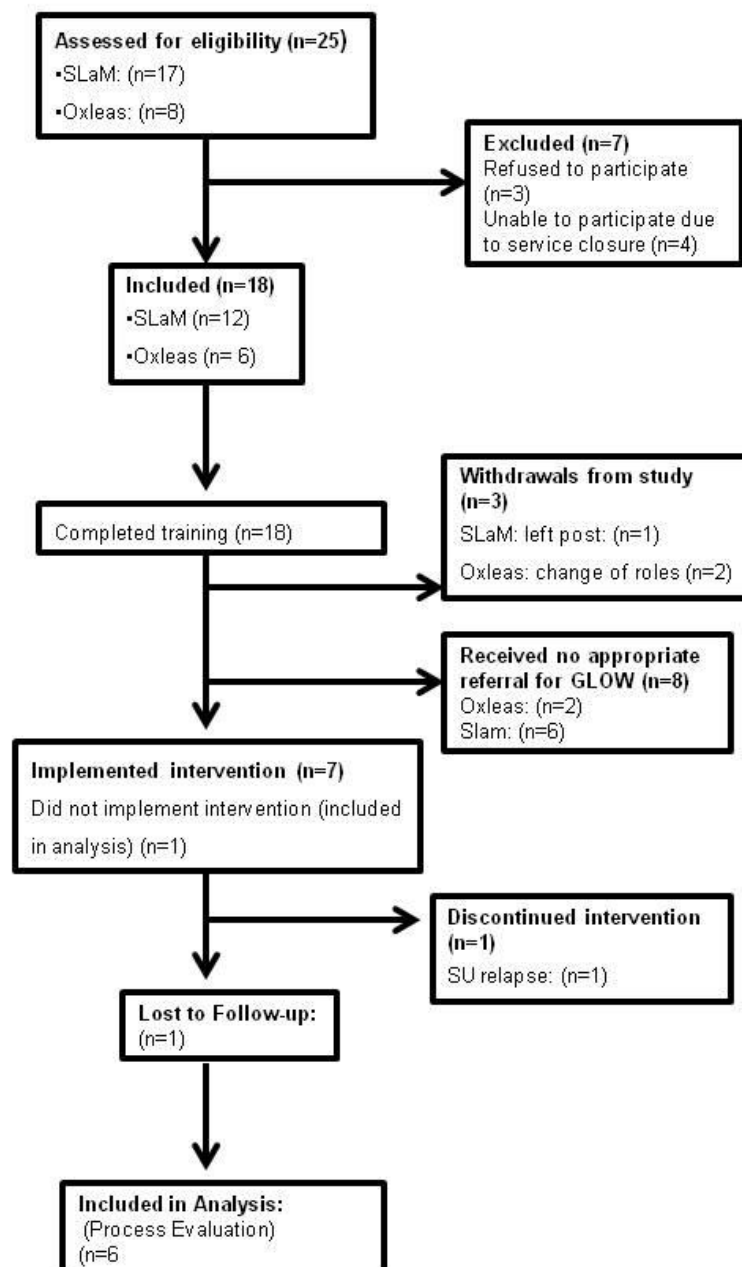
were to support people with diagnosed psychotic disorder to access community opportunities. The sixth OT working within a Community OT service was a Head OT providing OT assessments and advice to two Psychosis teams.

The gender distribution of the Occupational Therapists was unequal, so is not specified in the results to protect identity of the participants. All the OTs recruited into the study attended training regarding the use of the GLOW manual as described in Section 8.3.1. The training was carried out with the OTs during November and January. The OTs commenced screening for referrals to the study following training.

Figure 9.1 shows a flow diagram to depict the flow of Occupational Therapists through the study.



**Figure 9.1 Flow diagram of Occupational Therapists through the study**



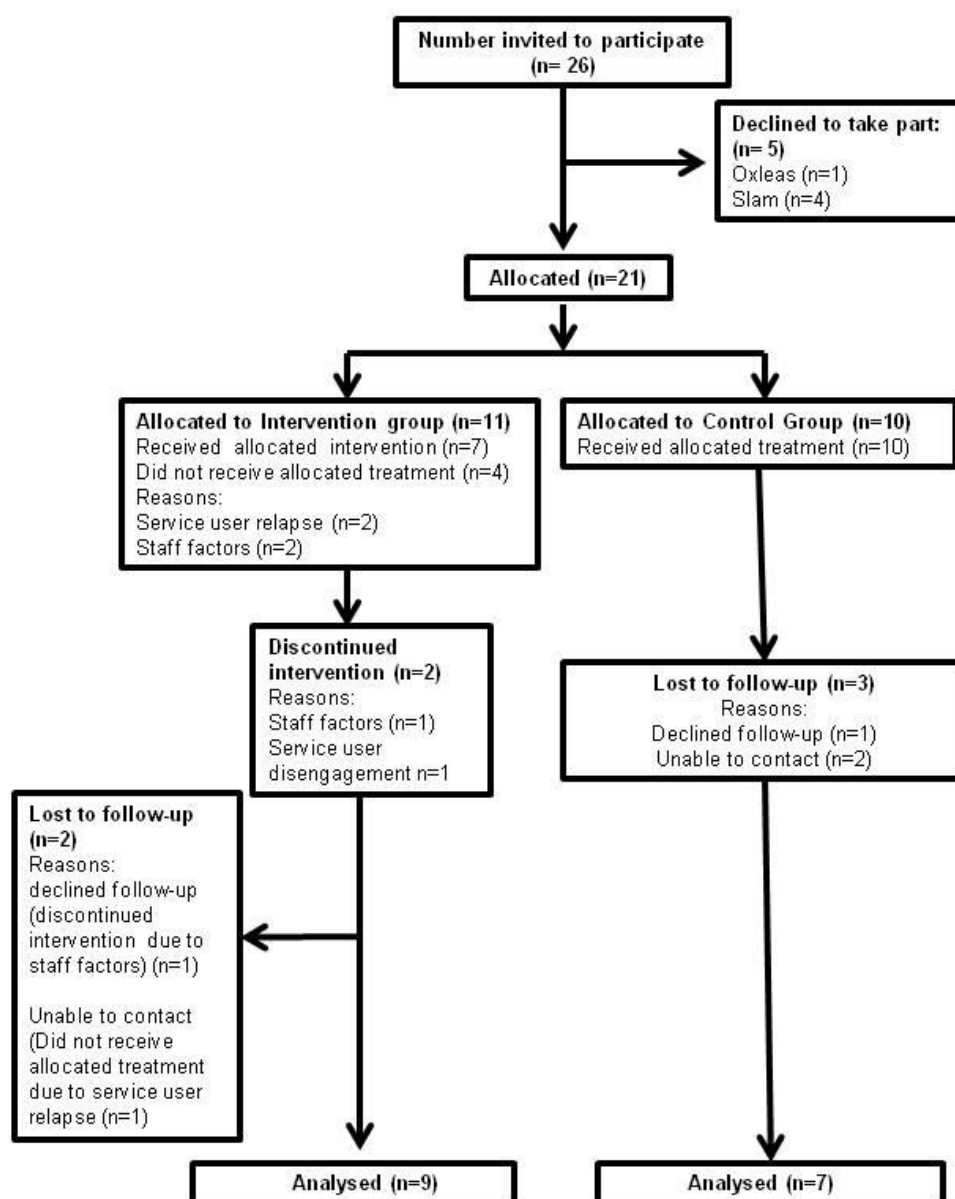
Twenty one service user participants were recruited from two NHS trusts into the study. Table 9.2 presents the demographic information for service user participants in the study.

**Table 9.2 Demographic information for service user participants (n=21)**

	Intervention	Control
<b>Gender</b>		
Male	4 (36%)	4 (40%)
Female	7 (64%)	6 (60%)
<b>Ethnicity</b>		
Black British	3 (27%)	5 (50%)
Black African	0	2 (20%)
White British	6 (55%)	2 (20%)
White Irish	1 (9%)	0
Asian	1 (9%)	1 (10%)
<b>Age (years)</b>		
Mean (standard deviation)	38.5 (9.71)	46.6 (10.38)
Range	25-52	30-64
<b>Site</b>		
<b>South London &amp; Maudsley Foundation Trust</b>		
Southwark	0	2
Lambeth	5	7
Lewisham	3	0
Croydon	1	0
<b>Oxleas NHS Foundation Trust</b>		
Bromley	1	1
Greenwich	1	0
<b>Accommodation</b>		
Independent	7	6
Supported	4	4
<b>Use of MH services</b>		
21 years or more	3	3
11- 20 years	2	3
6-10 years	3	2
0-5 years	3	2
<b>Number of hospital admissions</b>		
11-20	1	1
6-10	2	2
0-5	8	7
<b>Length of recent admission</b>		
1 year or more	3	1
8-11 months	0	2
4 - 7 months	3	2
1 – 3 months	2	5

There are differences between the two groups with regard to ethnicity, age and accommodation, however, given the small sample size statistical assessment of these differences is not appropriate. Figure 9.2 outlines the flow diagram of service user participants through the study, as recommended by the TREND guidelines used to report this study (Des Jarlais et al., 2004).

**Figure 9.2 Flow diagram of service user participants in the study**



### 9.1.1 ILSS-SR Baseline data

The primary outcome is ILSS-SR. Table 9.3 outlines the baseline scores for all participants (n=21).

**Table 9.3 ILSS-SR Baseline scores for all participants.**

<b>Participant</b>	<b>Baseline ILSS-SR score</b>
<b>Intervention Group</b>	
1	4.8
2	5.03
3	4.14
4	3.7
6	6.02
7	4.78
8	4.69
9	3.93
10	4.55
11	6.16
13	5.4
n=11	Mean 4.836
<b>Control group</b>	
5	5.22
12	3.46
14	5.22
15	3.77
16	4.5
17	5.26
18	5.56
19	4.27
20	7.07
21	5.88
n=10	Mean 5.02

An increase in score indicates an increase in independent living skills on the scale.

A summary of ILSS-SR Baseline scores for all participants in the intervention and control groups is presented in Table 9.4

**Table 9.4 Summary of Baseline Scores on ILSS-SR for all participants**

<b>Arm</b>	<b>N</b>	<b>Mean</b>	<b>Standard Deviation</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Range</b>
Intervention	11	4.836	0.787	3.70	6.16	2.46
Control	10	5.020	1.06	3.46	7.07	3.61

### 9.1.2 Baseline OCAIRS subset scores

Two subsets of the OCAIRS were used in the study to detect changes in habits and roles. Table 9.5 presents the baseline scores for the two subsets of OCAIRS for all participants in the study.

**Table 9.5 OCAIRS baseline scores.**

Participant	Baseline Habits	Baseline Interests
<b>Intervention</b>		
1	1	1
2	2	1
3	1	2
4	1	1
6	2	2
7	2	3
8	1	2
9	1	2
10	2	2
11	3	3
13	3	3
<b>Control</b>		
5	2	1
12	1	2
14	2	2
15	2	1
16	2	2
17	2	3
18	2	1
19	1	2
20	1	1
21	3	3

An increase in score indicates an increase in habits and interests.

Table 9.6 summarises the baseline, subscale scores for participants.

**Table 9.6 Mean baseline scores on OCAIRS subscales for all participants in the study**

Arm	Habits		Interests		Total	
	Mean Score	Range	Mean Score	Range	Mean score	Range
Intervention (n=11)	2	1-3	2	1-3	4	3-6
Control (n=10)	2	1-3	2	1-3	4	2-6

An increase in score indicates an improvement on the scale

### 9.1.3 MOHOST baseline scores

Baseline data were collected by the OTs for 7 of the 11 service user participants in the intervention group. Table 9.7 presents the baseline MOHOST scores for all seven participants.

**Table 9.7 Baseline MOHOST scores for participants at baseline.**

Participant n=7	Baseline MOHOST Scores
1	58
6	64
7	61
8	76
9	78
10	64
13	77
	Mean score 70

An increase in score indicates an increase in observed occupation performance.

From Table 9.7 we can see that the highest score achieved at baseline was 78. The maximum total score on the measure is 96. The mean subscale ratings for all seven participants are outlined in Table 9.8

**Table 9.8 Mean MOHOST subscale ratings for participants at baseline (n=7)**

MOHOST subscale	Mean Rating
Volition	2.82
Habituation	2.75
Communication and interaction skills	3.21
Process Skills	3.00
Motor Skills	3.61
Environment	2.75

From Table 9.8 it can be seen that habituation and environment are lowest subscale scores, indicating that the lack of routine and the environment inhibit performance of occupation for the participants.

#### **9.1.4 REIS-SF**

Data regarding REIS-SF was also collected by the OTs for service user participants in the intervention group only. Baseline data was collected by the OTs for 5 service user participants. Data was not completed for one participant and data for another participant was unable to be collected as the participant experienced a relapse in mental health symptoms. The mean baseline score was 45 with a minimum score of 42 and a maximum score of 47. Table 9.9 summarises the available data.

**Table 9.9 REIS-SF Baseline**

Participant	Baseline REIS-SF Score
6	46
7	46
8	43
9	42
13	47

## **9.2 Attrition of participants in the study**

### *Occupational Therapist participants*

Of the 18 OTs recruited to the study, seven OTs accepted referrals to implement GLOW with 11 service user participants. Four OTs implemented GLOW with five service user participants.

### *Service user Participants*

Of the 11 service user participants in the intervention group, five received GLOW, and a further four with endpoint data, were included in the intention to treat analysis. Of the ten service user in the control group, three were lost to follow up, resulting in seven being included in the analysis.

### *Service user participants who did not commence GLOW*

As can be seen from Figure 9.2, four service user participants did not commence GLOW, following their recruitment in to the study. Two service users became unwell and could not participate in the intervention and the remaining two did not commence as the OT did not implement GLOW with them.

### *Service users who did not complete GLOW as intended*

As can be seen from figure 9.2, three of the service user participants who commenced GLOW intervention, did not complete it. One of the service users was unable to complete the intervention as the OT had taken unplanned leave for several weeks, in addition to planned annual leave. The second service user was unable to complete the intervention as the OT reports that he disengaged from the OT and intervention after four weeks of the intervention.

## **9.3 Endpoint Results**

Sixteen service user participants, nine in the intervention group and seven in the control group were included in the analysis.

### **9.3.1 ILSS-SR scores**

Table 9.10 presents ILSS-SR baseline statistics for participants included in analysis.

**Table 9.10 Baseline Scores on ILSS-SR for participants included in analysis.**

<b>Arm</b>	<b>n</b>	<b>Mean score</b>	<b>Standard Deviation</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Range</b>
Intervention	9	4.97	0.77	3.93	6.16	2.23
Control	7	5.39	0.93	4.27	7.07	2.81

The ILSS-SR baseline, endpoint and change score for participants included in analysis is presented in Table 9.11.



**Table 9.11 Baseline, endpoint and change score on ILSS-SR for participants included in analysis.**

Participant	Baseline score	Endpoint score	change in scores
<b>Intervention Group n=9</b>			
Intervention Received			
7	4.78	6.2	1.42
8	4.69	6.72	2.03
9	3.93	5.61	1.68
10	4.55	5.28	0.73
13	5.4	6.36	0.96
Intervention not received			
2	5.03	5.37	0.34
3	4.14	4.42	0.28
6	6.02	6.6	0.58
11	6.16	5.56	-0.60
<b>Control group n=7</b>			
5	5.22	4.98	-0.24
16	4.5	6.3	1.80
17	5.26	4.53	-0.73
18	5.56	5.84	0.28
19	4.27	4.43	0.17
20	7.07	5.65	-1.42
21	5.88	5.84	-0.04

The mean subscale ILSS-SR change in score for both groups are presented in Table 9.12.

**Table 9.12 Mean subscale scores on ILSS-SR for intervention and control group**

Subscale	Change Score					
	Intervention (n=9)			Control (n=7)		
	Mean	min	max	mean	min	max
Appearance and Clothing	0.06	-0.11	0.22	0.06	-0.13	0.33
Personal hygiene	0.05	-1.7	0.17	-0.04	-.25	0.25
Care of personal possessions	0.21	-0.67	0.67	0.05	-0.17	0.5
Food preparation/Storage	0.02	-0.2	0.29	0.01	-0.29	0.29
Health maintenance	0.07	-0.3	0.25	0.19	-2.5	0.6
Transportation	0.01	-0.6	0.42	-.03	-0.2	00
Leisure and Community	0.17	-0.17	0.64	-0.01	-0.14	0.22
Job Seeking	-1.5	-1.5	-1.5	-2	-2	-2
Job maintenance*	N/A*			0.67	0.67	0.67

\*None of the participants in the intervention group were in employment at baseline.

As can be seen in Table 9.12, the mean change in score for the intervention group was higher than that of the control group in the areas of personal hygiene, care of personal possessions, and leisure and community. The maximum change in score was in the intervention group for care of personal possessions, with leisure change score for this group the second highest change.

### 9.3.2 OCAIRS scores

Change in scores for both groups on OCAIRS subscale questions are presented in Table 9.13 and indicate that the intervention group had higher change in scores than the control group.

**Table 9.13 OCAIRS scores for all participants included in analysis.**

Participant	Baseline Habits	Follow up Habits	Change score Habits	Baseline Interests	Follow up Interests	Change score Interests
Intervention						
Intervention Received						
7	2	3	1	3	3	0
8	1	4	3	2	4	2
9	1	3	2	2	3	1
10	2	3	1	2	3	1
13	3	3	0	3	3	0
Intervention not received						
2	2	2	0	1	2	1
3	1	1	0	2	2	0
6	2	3	1	2	3	1
11	3	2	-1	3	2	-1
Control						
5	2	2	0	1	1	0
16	2	3	1	2	3	1
17	2	3	1	3	3	0
18	2	2	0	1	2	1
19	1	1	0	2	2	0
20	1	1	0	1	1	0
21	3	3	0	3	3	0

From Table 9.13 we can see that participants in the intervention group who received GLOW, showed improvements in both habits and interests subscales, with habits change scores showing greatest change. Four participants in the control group had no change in scores in both the areas of habits and interests. Two participants in the intervention group had no change in

score at end point, one of these participants did not receive GLOW. Additionally, one participant in the intervention group saw a decrease in scores at end point, this participant did not receive any of the GLOW intervention.

### 9.3.3 MOHOST Scores

MOHOST endpoint scores were collected by the OTs for five participants. Table 9.14 outlines a summary of MOHOST scores for five participants in intervention group where data was collected.

**Table 9.14 MOHOST change scores for intervention group participants (n=5)**

Participant	Baseline	Endpoint	Change score
Received intervention (n=5)			
7	61	65	4
8	76	86	10
9	78	84	6
10	64	missing	
13	77	86	9

To examine the effect of the intervention across the components of MOHO, Mean MOHOST subscales scores for the participants are presented in Table 9.15

**Table 9.15 Mean baseline, endpoint and change score MOHOST subscale scores**

MOHOST subscale	Baseline Mean Rating	Endpoint Mean Rating	Change score
Volition	2.82	3.12	0.30
Habituation	2.75	3.19	0.44
Communication and interaction skills	3.21	3.56	0.35
Process Skills	3.00	3.56	0.56
Motor Skills	3.61	3.69	0.08
Environment	2.75	3.37	0.62

From Table 9.15 we can see that mean MOHOST scores for environment, process skills and habituation show the greatest improvement in score.

### 9.3.4 REIS-SF scores

REIS-SF Baseline, endpoint and change scores are presented in Table 9.16.

**Table 9.16 Baseline, Endpoint and change scores on REIS-SF for intervention group**

Participant	Baseline	Endpoint	Change score
Completed the intervention			
7	46	50	4
8	43	Missing	NA
9	42	57	15
10	Missing	Missing	
13	47	56	9
Did not complete the intervention			
6	46	Missing	NA

Three participants for whom data is available show an increase in score on this measure, indicating changes regarding environmental impact on occupational performance. The results of each of the seven objectives of the study will be presented individually, followed by a summary of the overall findings.

## 9.4 Outcome Objectives

### 9.4.1 Objective 1: Estimate effectiveness of intervention

To test for difference in change scores between the intervention and control group, intention to treat analysis was carried out using the Mann-Whitney U test. Median latencies in the intervention group was 0.726 and control group was -.04; the distributions in the two groups differed significantly (Mann-Whitney U= 13,  $z = -1.95$ ,  $p = .05$  two-tailed). This indicates a significant difference in change in scores between the participants receiving GLOW intervention, and the control group.

Sub analysis including only participants in the intervention group who received GLOW as intended ( $n=5$ , median=0.50) showed an increase in significance of difference in change score, for the intervention group (Mann-Whitney U=4,  $z = -2.19$ ,  $p = .028$  two-tailed).

To further investigate change, potential improvement analysis was carried out, using the equation:

$(\text{Post-test score} - \text{pre-test score}) / (\text{maximal possible score} - \text{pre-test score})$ , where the maximum score for ILSS-SR is 9.

Table 9.17 presents the relative improvement score for all participants included in analysis.

**Table 9.17 Percentage Potential improvement score on ILSS-SR for participants included in analysis.**

Participant	Potential improvement score %
Intervention group	
Received Intervention	
7	33
8	47
9	33
10	16
13	26
Mean	31
Did not receive intervention	
2	08
3	05
6	19
11	-2
Mean	3
Overall mean for intervention group	2
Control Group	
5	-6
16	4
17	-2
18	8
19	3
20	-7
21	-1
Mean	-7

From Table 9.17 it can be seen that four of the five participants who received the intervention had a higher percentage of potential improvement of ILSS-SR score than any other participant.

Changes in scores for three other measures were investigated. The details of the areas of improvement in OCAIRS, MOHOST and REIS-SF will be outline in case studies next.

*Summary of outcomes for the five participants who received GLOW*

In order to more closely examine the changes in occupational performance for the five participants who received GLOW as intended, the participants scores and areas of change

indicated on the outcome measures and clinical assessment tools, are described. Meaningful changes in occupational performance that the participants achieved will be examined, using data from semi-structured interviews with OTs. The service users' responses to the post-intervention questions regarding most and least helpful part of the intervention are also integrated into this section.

### **Participant 7**

This participant was a service user of an early intervention team. He had moved into accommodation in a new area unfamiliar to him following discharge from hospital. Prior to his admission he lived with mother and siblings. Table 9.18 outlines the changes in occupational performance scores.

**Table 9.18 Occupational performance scores for Participant 7**

<b>ILSS-SR</b>	Baseline Score	Endpoint Score	Change in Score
<b>Total</b>	4.78	6.2	1.42
Appearance and Clothing	0.89	1.00	0.11
Personal hygiene	0.83	1.00	0.17
Care of personal possessions	0.66	1.00	0.33
Food preparation/Storage	0.71	1.00	0.29
Health maintenance	1.00	1.00	0
Transportation	0.6	0.6	0
Leisure and Community	0.6	0.67	0.6
Job Seeking	0.5	N/A	NA
Job maintenance	N/A*	N/A	N/A
<b>OCAIRS</b>			
<b>Total</b>	5	6	1
Habits	2	3	1
Interests	3	3	0
<b>MOHOST</b>			
<b>Total</b>	61	65	4
Motivation for Occupation	10	9	-1
Pattern of Occupation	9	10	1
Communication & Interaction Skills	11	12	1
Process Skills	9	9	0
Motor Skills	14	14	0
Environment	8	11	3
<b>REIS-SF</b>			
<b>Total</b>	46	50	4
Physical Space	13	17	4
Resources	8	8	0
Social Support	12	11	-1
Opportunities	13	14	1

The participant's potential improvement score was 33%. Improvement was shown in the areas of appearance and clothes, personal hygiene and care of personal possessions, habits, pattern of occupation, communication and interaction, environment, physical space and opportunities for OP. These can be summarised as an increased in time spent in satisfying occupations and increased satisfaction with daily routine.

Both the participant and OT identified post-intervention changes in occupation, including establishing a weekly routine involving attending a music course and football group, establishing a positive home environment including better resources for self-care (cooking equipment) and leisure (internet access). The participant stated that he plans to return to a previously attended college course on electrical engineering. This participant had no negative comments regarding GLOW, and indicated that the intervention has helped him become more self-aware:

*"It helped me to understand myself, and how to be independent and get involved in things outside my flat."*

### **Participant 8**

This participant lives with her husband and two children ages eight and 11 before and after her admission to hospital. She had been in hospital for four months prior to commencing GLOW. Table 9.19 outlines the changes in occupational performance scores.



**Table 9.19 Baseline, endpoint and change scores for Participant 8**

<b>ILSS-SR</b>	<b>Baseline Score</b>	<b>Endpoint Score</b>	<b>Change in Score</b>
<b>Total</b>	4.69	6.72	2.03
Appearance and Clothing	0.78	1.00	0.22
Personal hygiene	0.91	1.00	0.09
Care of personal possessions	0.33	1.00	0.67
Food preparation/Storage	0.85	1.00	0.15
Health maintenance	0.75	1.00	0.25
Transportation	0.8	0.8	0
Leisure and Community	0.27	0.92	0.65
Job Seeking	NA	NA	NA
Job maintenance	NA	NA	NA
<b>OCAIRS</b>			
<b>Total</b>	3	8	5
Habits	1	4	3
Interests	2	4	2
<b>MOHOST</b>			
<b>Total</b>	86	86	0
Motivation for Occupation	12	14	2
Pattern of Occupation	11	13	2
Communication & Interaction Skills	16	16	0
Process Skills	15	12	-3
Motor Skills	16	15	-1
Environment	16	16	0
<b>REIS-SF</b>			
<b>Total</b>	43	Missing	N/a
Physical Space	15	Missing	N/a
Resources	3	Missing	N/a
Social Support	8	Missing	N/a
Opportunities	17	Missing	N/a

The participant's potential improvement score was 47%. Improvement was shown in all areas of ILSS-SR except for transportation and job subscales. Improvements were also shown in habits, interests, motivation for occupation and pattern of occupation. These can be summarised as changes in developing a satisfying routine of leisure outside the home and an increase in her ability to care for herself and home environment.

The participant had no negative comment to make regarding GLOW, when asked to comment on not useful aspects of it. The participant stated that the experience of receiving GLOW intervention was very positive. She stated GLOW helped her to find things to do in the community, and what she specifically found beneficial, was that it gave her courage to:

*“actually enrol on courses and to attend”.*

This indicates that she had planned to attend courses and that GLOW enabled her to take action and enrol on a course and subsequently attend.

### **Participant 9**

This participant had moved from 24 hour supported housing to a self contained apartment with floating support following discharge from hospital. The new accommodation was in a new and unfamiliar area to the participant. Table 9.20 outlines the changes in occupational performance scores.

**Table 9.20 Baseline, endpoint and change scores for Participant 9**

	Baseline score	Endpoint score	Change in Score
<b>ILSS-SR</b>			
<b>Total</b>	3.93	5.61	1.66
Appearance and Clothing	0.89	1.00	0.11
Personal hygiene	0.67	0.73	0.06
Care of personal possessions	0.33	0.8	0.47
Food preparation/Storage	0.71	1.00	0.29
Health maintenance	0.8	1.00	0.2
Transportation	0.25	0.67	0.42
Leisure and Community	0.33	0.42	0.08
Job Seeking	NA	NA	
Job maintenance	NA	NA	
<b>OCAIRS</b>			
<b>Total</b>	3	6	3
Habits	1	3	2
Interests	2	3	1
<b>MOHOST</b>			
<b>Total</b>	78	84	6
Motivation for Occupation	14	14	0
Pattern of Occupation	12	13	1
Communication & Interaction Skills	13	15	2
Process Skills	13	15	2
Motor Skills	14	14	0
Environment	10	12	2
<b>REIS-SF</b>			
<b>Total</b>	42	57	15
Physical Space	13	18	5
Resources	8	10	2
Social Support	9	13	4
Opportunities	12	16	4

The participant's potential improvement score was 33%. Improvement was shown in all four measures. These can be summarised as changes in her daily routine of occupations, access to local neighbourhood and time spent engaged in leisure or self-care occupations in her home.

Despite the modest change in MOHOST score for this participant, the Occupational Therapist identified that the service user had made significant progress in improving her occupational

performance. As a result the OT was unsure if she had rated the service user accurately at baseline, as she wasn't very familiar with MOHOST. The OT also indicated that as MOHOST rates a person's OP into one of four categories, perhaps the measure wasn't sensitive enough to changes in this population. This participant identified that GLOW had helped her to set goals regarding organising things in her home and finding things to do in the community.

#### **Participant 10**

This participant was a service user of a psychosis team, the OT implementing the intervention was also her care co-ordinator. She lives with her partner and her teenage son. Table 9.21 outlines the changes in occupational performance scores.

**Table 9.21 Baseline, follow up and change scores for Participant 10.**

	<b>Baseline score</b>	<b>Endpoint score</b>	<b>Change in Score</b>
<b>ILSS-SR</b>			
<b>Total</b>	4.55	5.28	0.73
Appearance and Clothing	1.00	0.88	-0.11
Personal hygiene	0.75	0.92	0.17
Care of personal possessions	0.5	1.00	0.5
Food preparation/Storage	1.00	0.8	-0.2
Health maintenance	0.83	0.8	-0.03
Transportation	0.2	0.6	0.4
Leisure and Community	0.27	0.27	0.00
Job Seeking	NA	NA	
Job maintenance	NA	NA	
<b>OCAIRS</b>			
<b>Total</b>	4	6	2
Habits	2	3	1
Interests	2	3	1
<b>MOHOST</b>			
<b>Total</b>	64	Missing	
Motivation for Occupation	12	Missing	
Pattern of Occupation	12	Missing	
Communication & Interaction Skills	13	Missing	
Process Skills	10	Missing	
Motor Skills	16	Missing	
Environment	11	Missing	
REIS-SF	Missing	Missing	

The participant's potential improvement score was 16%. Improvement was shown in ILSS-SR and OCAIRS. The reduced score in the area of health maintenance occurred as the participant realised at follow up, that she wasn't very good at looking after herself and perhaps this was why she became unwell in the past. The score doesn't reflect the positive acknowledgement of a problem by the participant.

This participant received GLOW with lowest fidelity to the intervention manual, indicating that she didn't receive GLOW to the standard that the other four participants did.

### Participant 13

The participant moved from floating support to 24 hour supported accommodation to ensure she had access to support regarding her mental health symptoms. Table 9.22 outlines the changes in occupational performance scores.

**Table 9.22 Baseline, follow up and change scores for Participant 13**

	Baseline Score	Endpoint Score	Change in Score
<b>ILSS-SR</b>			
<b>Total</b>	5.4	6.36	0.96
Appearance and Clothing	0.89	1.00	0.11
Personal hygiene	1.00	0.83	-0.17
Care of personal possessions	0.5	1.00	0.5
Food preparation/Storage	1.00	1.00	0
Health maintenance	1.00	1.00	0
Transportation	0.6	0.8	0.2
Leisure and Community	0.42	0.73	0.31
Job Seeking	NA		
Job maintenance	NA		
<b>OCAIRS</b>			
<b>Total</b>	6	6	0
Habits	3	3	0
Interests	3	3	0
<b>MOHOST</b>			
<b>Total</b>	77	86	9
Motivation for Occupation	10	13	3
Pattern of Occupation	13	15	2
Communication & Interaction Skills	14	14	0
Process Skills	13	14	1
Motor Skills	15	16	1
Environment	10	14	4
<b>REIS-SF</b>			
<b>Total</b>	47	56	9
Physical Space	15	18	3
Resources	9	12	3
Social Support	13	15	2
Opportunities	10	9	-1

The participant's potential improvement score was 26%. Improvement was shown in ILSS-SR, MOHOST and REIS-SF scores. These can be summarised as improvements in important areas

to the participant such as leisure and community. This participant identified that the GLOW intervention helped her find her way around her new neighbourhood and to get used to new bus routes. She identified the best part of the intervention as the support she was able to access a swimming pool, which she now goes to on a regular basis.

*Process of change expected from Model of intervention*

Figure 6.2 outlined the model of the intervention, which outlines the process of change expected during the intervention. Within this model, changes are expected within the components of the Model of Human Occupation, in the areas of volition, habituation and performance. From the above description of the changes occurring for each of the participants who received GLOW, it can be observed that positive changes have taken place within motivation for occupation, routines and habits and increase in self knowledge regarding occupational performance. Table 9.23 summarises the changes components of Model of Human Occupation for 5 participants who received GLOW.

**Table 9.23 Changes in components of Model of Human Occupation for 5 participants who received GLOW.**

<b>Volition</b>		Increase score	Decrease score	No Change in score
Values	<b>OCAIRS</b> (Interests) <b>MOHOST (n=4)</b> (Motivation for Occupation)	3	0	2
Interests				
Personal Causation		2	1	1
<b>Habituation</b>	<b>OCAIRS</b> (Habits)	4	0	1
Habits				
Roles	<b>ILSS-SR</b> (leisure and community) <b>MOHOST (n=4)</b> (pattern of occupation)	5	0	0
		4	0	0
<b>Performance</b>	<b>ILSS-SR</b> (Total score)	5	0	0
Physical attributes				
Mental Attributes	<b>MOHOST (n=4)</b> motor skills process skills	2	1	1
		2	1	1
Environment	<b>MOHOST (n=4)</b> (environment) <b>REIS-SF</b>	3	0	1
		3	0	0

From Table 9.23 we can see that change took place in all components of the model, however, not all participants experienced a change in all areas. REIS-SF and MOHOST are observational

measures, and therefore will yield different results to self-report measures. Additionally, the two measures were administered by different clinicians, affecting the reliability of the results.

#### *Summary of Effectiveness of Intervention*

Participants in the intervention group experienced a greater improvement on ILSS-SR than those in control group ( $p = .05$ ). Sub-analysis of difference in score between those participants in intervention group who received GLOW as planned and those in control group indicate that those who received GLOW demonstrated higher increase of score on ILSS-SR than control group. Detailed presentation of change scores on all measures for those who have received GLOW, further identify the positive effect the intervention has had on their occupational performance. This indicates that GLOW demonstrates preliminary evidence of effectiveness.

#### **9.4.2 Objective 2 Test appropriateness of primary outcome measure**

Floor affects were not present at baseline or endpoint for total scores. Ceiling effects were not present at baseline or endpoint for total scores. However, for five of the nine subscales at baseline a maximum score was given to participants as follows: At endpoint, maximum scores were given to participants on the same subscales in addition to health maintenance. The percentage maximum scores are presented in Table 9.24.

**Table 9.24 Percentage of maximum scores received for subscales for participants included in analysis (n=16)**

<b>Subscale</b>	<b>% maximum score at baseline</b>	<b>% maximum score at endpoint</b>
Appearance and Clothes	25	43
Personal hygiene	24	18
Care of personal possessions	25	37
Food preparation/storage	31	37
Health maintenance	37	75

The data presented in Table 9.24 indicate that ceiling effect was present in four subscales at baseline and five out of nine subscales of ILSS-SR at endpoint. The data indicates the measure was not sensitive to change for the participants included in the above percentages.

Floor affects were present for scores on the two subscales relating to job seeking and job maintenance. Job seeking subscale questions were rated Not Apply for 13 of the 16 participants included in analysis, at baseline and 15 participants at endpoint. Job maintenance subscale questions were rated Not Apply for 15 of the participants included in analysis at baseline and 15 at endpoint.



### **9.4.3 Objective 3 Assessing context: To investigate the contextual factors impacting on the intervention delivery**

#### *Socio-political context*

During 2011 the UK economy was still recovering from a recession, prior to returning to recession in 2012. In February 2011, trade unions reported that the NHS was planning to lose 50,000 jobs countrywide (BBC, 2011). The NHS at this time was disinvesting services confirming the trade union reports of job losses. This disinvestment occurred in both NHS trusts participating in this study.

A further socio-political issue at this time was changes to benefits for people with a disability. In April 2011, the Department for Works and Pensions announced that Incapacity Benefit (IB) was being replaced by Employment and Support Allowance, in addition to the introduction of the Work Capability Assessment. This meant that for the first time regular reassessments of needs are carried out for those in receipt of this benefit (Department for Work and Pensions, 2011). The introduction of regular assessment of capability to work has caused anxiety for those on ESA regarding loss of this benefit following the assessment. For many mental health service users of the NHS in receipt of benefits, the change from IB to ESA resulted in a financial loss. Further changes are taking place from April 2013 when Disability Living Allowance (DLA) will be replaced by Personal Independence payment. The changes and planned changes to the benefit system resulted in increased anxiety for mental health service users regarding fear of loss or cut in benefits and the financial consequences, which may have an impact on their mental health. One of the OTs reported that this increased anxiety may have contributed to the relapse and readmission to hospital of one of the participants in the study that she had planned to implement GLOW with.

#### *Organisational Context*

In 2009, South London & Maudsley NHS Foundation Trust became part of an Academic Health Science Centre (AHSC), incorporating two other NHS trusts and King's College London. AHSCs seek to combine basic and translational health research, clinical care and education to create world-leading improvements in healthcare. For South London & Maudsley NHS Trust, this meant changing borough based clinical services to condition specific services. Clinical Academic Groups (CAG) replaced these borough based services, bringing condition specific clinical services and researchers of that condition together. This involved division of adult mental health services into a Psychosis CAG, Mood, Anxiety and Personality Disorder CAG and Psychological Medicine CAG. This process of changing Community Mental Health Team structures commenced in 2010, and during 2011 the process involved moving clinical cases between team caseloads. The OTs in the study reported that this caused anxiety and increase workload to the community mental health staff.

Lead OTs per clinical area provide professional supervision to OTs but do not line manage them, this results in OTs being line managed by team leaders who cascades team tasks and responsibilities to all team members. The lead OTs can negotiate and influence the team leaders' decisions regarding role of OT, but cannot directly instruct the OTs to do specific tasks or responsibilities. Therefore, the involvement of OTs in research may not always be supported by the team leader and during this study, the Lead OTs had changed jobs roles and did not have the capacity to influence and negotiate OT time within the teams, which resulted in less support from several team leaders, resulting in lack of time to recruit service users to the study.

#### *Team structures*

Additionally, in October 2011, the Assertive Outreach Teams in the four boroughs in South London & Maudsley NHS Foundation Trust were closed. Clients on their caseloads were moved to local Psychosis teams, and resulted in higher caseloads of up to 30 service users for the clinicians.

The clinicians were moved to work within existing community services in the trust. This resulted in two psychosis teams with 30 clinicians on each team within one Borough. One of the OTs identified clinical pressure as a factor impacting on implementation of GLOW. The OT identified that the team's focus since the closure of Assertive outreach team and reconfiguration of teams, has been on crisis response. She indicated that team members are:

*"running around like headless chickens."*

For the two OTs working in the Psychosis teams, they identified that their role as care co-ordinator to service users on their caseload always came first:

*"Whenever there is a crisis, you just have to be there, you know follow up clients who haven't had their depot, take collection of FB10s, you need to deliver prescriptions and medications, I mean, all those things."*

For one of the OTs in care co-ordination role, they felt their role as an OT on the team had not been discussed with the team or team leader. The OT indicated the reason for this as the absence of the Community Head Occupational Therapy, as the post holder was on maternity leave and no cover for the person was in place. The OT in the study indicated this impacted on the ability to plan or decide on OT role within the team.

One of the teams where four OTs were recruited from was disinvested and a new service launched in April 2012. This resulted in change in focus of service. One of the OTs accepted referrals for two service users for GLOW, but did not implement the intervention. This OT indicated that the change in service distracted her from focusing on implementing the intervention and that she was anxious about implementing a new intervention. The OT also indicated that the current focus of the team was on other aspects of the service, for example, using standardised assessments and not on interventions so this also took her attention away from implementing GLOW.

The team leader of one of the OTs met with the researcher and OT to support the implementation of GLOW. The team leader identified that GLOW would address the needs of service users of their team and would support the OT to delineate the role within the team.

The second intervention site for the study was Oxleas NHS Foundation Trust. During recruitment of OT and service user participants into the study, service reconfiguration of adult community mental health services took place. This resulted in a number of service users being seen on outpatient only basis, without care co-ordination. It was planned that the community OTs would assess many of these to establish their needs regarding independent living skills and refer on to necessary agencies. Therefore the two OTs participating in the study, were no longer able to accept referrals from the wards and implement GLOW.

### *Local Context*

The study took place in six boroughs in South East London. The English Indices of Deprivation 2010, ranked one of the boroughs, Lambeth as having the 14<sup>th</sup> highest level of deprivation in England, with three other boroughs within the 25 most deprived boroughs (Department for Communities and Local Government, 2011). Croydon was the least deprived borough in the study, being ranked 99. The intervention was informed by service users and clinicians from South East London, and so the intervention aims to meet the needs of people with mental health problems in the local area.

One of the OTs identified that community resources were limited at the time, with long waiting lists of services such as Home and Dry, a painting and decorating service for people with mental health problems, where their current home environment is negatively affecting their mental health. The Occupational Therapist indicated the waiting list for this service was very long and so for the service user it was uncertain when their home environment could be painted and a new curtain rail installed.

Another local resource one of the service user participants in the study wanted to access was currently unavailable and it was unclear if the service would re-open. The Occupational Therapist indicated that the current economic climate had affected the availability of these services.

One of the OTs working generically in a Psychosis team clearly acknowledged the challenges provided by the context of the study:

*“I think, the time you’ve done this.... you know, I think if benefits weren’t being cut, if there wasn’t this pressure on the service, I think they all play a part”*

A synthesis of the effects of the contextual factors on the study is shown in Table 9.25

**Table 9.25 Contextual factors affecting the study**

<b>Context</b>	<b>Effect on study</b>
<b>Socio political</b>	
2011 Economic impact of Recession	NHS disinvestment leading to anxiety in staff regarding possibility of redundancy  Changes to benefits leading to distress, a possible contributor to service users relapse within the study.
<b>Organisational</b>	
2010-2011 Change from Borough managed services to clinical diagnosis based services	Movement of clinical caseloads, increasing workload on staff in the study.  Implementation of new clinical systems being put in place, increasing workload for staff in the study
<b>Team structures</b>	
Closure of Assertive Outreach team leading to merging of teams to form Psychosis teams	Increase in caseload for the clinicians in the study who care co-ordinate  Two Clinicians in the study moved team base and their team merged with other Psychosis teams
Disinvestment and restructuring of an OT lead service	Four OTs were unable to take part in the study as their posts were being deleted in following month.  Two of the OTs in the study formed a newly formed service, resulting in increase administration time in forming new team structures, distracting from clinical tasks in study.
<b>Local Context</b>	
Economic effect of limiting social resources	Reduced availability of existing limited resources for service users impacting on their home environment.

#### **9.4.4 Objective 4 Acceptability of the intervention**

All seven Occupational Therapists who accepted referrals to implement GLOW, reported on the acceptability of the intervention. The respondents answered all five questions positively, indicating that the intervention was acceptable to implement, and that they would use the intervention again with people who have left hospital. They also indicated that they believe the intervention would not cause any harm and that they would recommend it to other occupational Therapists.

However, results from the Occupational Therapists' interviews, indicate that for one service user, the OT was tentative about the high intensity engagement for the first four weeks, as she felt it maybe too intrusive. She reported that the service user has disengaged from services several times in the past and as a result she was concerned the intervention may intrude too much and result in him disengaging. This indicates, that the OT identified that the intervention may not be acceptable to all service users, despite the OT or service user indicating this when

answering acceptability questionnaire. It may also indicate that the intervention is not acceptable for some OTs to implement if they are reluctant to address issues in home environment.

The Occupational Therapists gave additional information when answering the questions regarding the acceptability of the intervention. One Occupational Therapist indicated that her team had discussed implementing the intervention, with service users who have moved residential placement, for example stepping down a level of support. A further Occupational Therapist indicated they would use GLOW routinely in practice, by screening service users being discharged from the wards that may benefit from GLOW, and offering GLOW to them.

Service users who received all 16 weeks of the intervention were also asked the same five questions regarding the acceptability of the intervention. All five service users reported that the intervention was acceptable to them, would not cause any harm, and was useful following discharge from hospital. All the service users also indicated that they would recommend GLOW to other service users leaving hospital and that if they did need such an intervention again, they would like to receive GLOW.

#### **9.4.5 Objective 5 Fidelity to intervention manual**

The four Occupational Therapist participants who implemented GLOW completed a fidelity questionnaire. The results are outlined in Table 9.26

**Table 9.26 OT-rated fidelity for all participants (n=5) who completed GLOW**

<b>Fidelity %</b>	<b>Intervention Component</b>
100	MOHOST at baseline
100	MOHOST at Endpoint
100	REIS at baseline
60	REIS at Endpoint
100	Interest Checklist at baseline
0	Interest Checklist at endpoint
80	Therapeutic mode- Instructive
100	Therapeutic mode- encouraging
40	Therapeutic mode- advocating
100	Therapeutic mode- problem solving
100	Therapeutic mode- collaborating
100	Developing self-management of Occupational Performance
100	Environmental Enhancements & considerations
100	Activity Grading
60	High Intensity four weekly visits completed
100	Medium Intensity six weeks completed
100	Low Intensity six weeks completed

All OTs carried out the intervention for 18 weeks and implemented the three levels of intensity. All OTs completed MOHOST and REIS-SF assessments with the service user participants at baseline. Three of the five therapeutic modes, encouraging, problem solving, and collaborating, were used by all OTs. Complete fidelity was not met for all components. The reasons for lack of fidelity were discussed during the semi structured interviews with the OTs and are now outlined in Table 9.27.

**Table 9.27 Summary of reasons for low fidelity of components of intervention**

<b>Component not completed</b>	<b>Clinician Reason</b>	<b>Researcher explanation</b>
End point REIS-SF	Not aware it should be re-administered  OT did not expect change so did not re-administer	
Interest checklist at endpoint	Not aware it should be re-administered	
Instructing mode	Least familiar mode felt difficult to administer.	The researcher noticed that the subject of therapeutic modes was overall talked about for a much shorter time than other aspects of the intervention.
Advocating mode	situations did not arise where an advocate mode was needed.	
4 week High Intensity (weekly visits)	family was offering a lot of support  personal assistant began working with participant	

**9.4.6 Objective 6 Assess dose delivered and dose received***Dose delivered*

The results from the questionnaires and semi structured interviews with OT participants indicated that two OTs did not deliver the high intensity component of the intervention as set out in the manual. The two OTs did not visit and provide a follow-up phone call each week for the four weeks. The aim of the weekly visits was to provide a high level of contact with the service user to support them to meet their basic needs regarding self-care, as prioritised by service users. In both cases other forms of support were available to the service users (family for one, personal assistant for the other). The OTs therefore felt weekly visits were not necessary. The intended frequency of meetings took place during the medium and low intensity stages of the intervention.

*Dose received*

Service user participants who received the GLOW intervention were asked questions at follow-up about the intervention. The service users identified that they had completed an assessment of their skills (MOHOST), their home environment (REIS-SF), and identified their leisure interests through use of the Interest Checklist. All the service users indicated that the OT supported them to identify areas that they would like to improve in their home environment, to enable them to carry out activities of daily living. Four of the five service users stated that the OT Worked with them in a way that gradually gave them more responsibility for tasks, while the OT became less involved in tasks over time.

## **Barriers and facilitators to implementing GLOW**

Semi structured interviews were carried with the six Occupational Therapists who accepted referrals for GLOW intervention, in addition to the questionnaires regarding acceptability of the intervention and fidelity to the manual. Information regarding barriers and facilitators to using GLOW was gathered. The data was analysed using thematic analysis and the following themes were identified.

### **Barriers to implementing GLOW**

Four themes were identified.

#### **Barrier 1: Generic working**

Two of the OTs who implemented GLOW with service users worked fulltime as care co-ordinators in community mental health teams. These OTs stated that the focus of their teams is on crisis management:

*“Whenever there is a crisis, you just have to be there, you know, follow up clients who haven’t had their depot, you need to deliver prescriptions, medications, I mean, all those things.”*

The second OT highlighted generic working as a barrier to implementing GLOW.

*“in the context of generic working with focus on crisis management, it’s difficult to implement. But I think it shouldn’t be difficult”*

#### **Barrier 2: OT confidence**

One OT who had accepted referrals for two service users but did not use GLOW with them, indicated that she felt anxious and lacking in confidence in using a new intervention, which she stated:

*“I kind of just lost my way”*

#### **Barrier 3: Service reconfiguration**

The OT referred to in the previous paragraph, also indicated that a barrier to her implementing GLOW was the major restructuring of the community Occupational Therapy service the OT worked in. This involved introducing standardised assessments and establishing parameters of service.

*“if things hadn’t been so unsettled, I got caught up in other things”*

#### **Barrier 4: Supervision and support**

Barriers were also identified by the researcher on completion of the study. Support regarding implementing the intervention was less than the level of support planned. The researcher had planned to offer fortnightly phone or face to face supervision with the OTs during the implementation of the intervention. However, due to the additional time required to increase



recruitment of OTs and service users into the study, the researcher could not offer this level of support. Instead, the researcher agreed to contact the OTs every two weeks by phone or email and for the OTs to phone the researcher in between with any questions.

### **Facilitators to implementing GLOW**

Four facilitators were identified.

#### **Facilitator 1: Whole team Implementation**

One OTs indicated that if all the OTs on her team implemented GLOW, it would enable the OT to discuss GLOW within team meetings to gain peer support and enable her to discuss it regularly with colleagues and in supervision. This would support her to carry out GLOW as part of everyday practice.

#### **Facilitator 2: Using the intervention more than once**

Of the four OTs who completed GLOW with service user participants, only one used it with more than one service user. The other three OTs participating in the study indicated that if they had the opportunity to use GLOW more than once, it would enable them to become more familiar with the process and enable them to embed it into their clinical practice.

#### **Facilitator 3: OT specific role**

One of the OTs was motivated to use GLOW because she wanted to increase the clarity of her role as OT on the team. One of the OTs stated that:

*“it gave me permission to focus intensively on OT, and for the team, to see results”*

#### **Facilitator 4: Team leader support**

One team leader was very motivated to ensure GLOW was implemented by the OT. She met with the researcher and the OT to discuss all aspects of the intervention, including promotion of the intervention to team members and recruitment to the study. The team leader identified a further application of GLOW, by using it with service users who had recently changed level of accommodation, which is often in a new unfamiliar neighbourhood. We agreed that the researcher would support this implementation of GLOW, following completion of the pilot study, if appropriate. The OT participant accepted three referrals to use GLOW and stated that the team had identified the benefits of using GLOW.

### **9.4.7 Objective 7 Assess recruitment rate to study**

#### *Recruitment of OTs*

Eighteen OTs were recruited to the study over four months. From figure 9.1, it can be seen that of the 18 OTs who were recruited to the study and received training regarding implementing GLOW, six OTs completed the study. Three OTs withdrew from the study, one OT left the trust and two, who worked in same team, had to withdraw as their team function changed to focus on

outpatients rather than recently discharged from hospital. Eight OTs did not receive or identify any suitable referrals to implement GLOW. One OT who accepted referrals for two service users, did not complete GLOW with either service user.

There were three main challenges to recruiting Occupational Therapists into the study. Firstly, the declining number of OTs working in profession specific way the community, due to disinvestment in services reduced the number of OTs eligible to participate. Secondly, the OTs working in generic roles, whilst consenting to take part, found it difficult to recruit to the study due to time limitations. Three OTs who work generically declined to take part due to existing work demands. In one case a team with two OTs participating in the study, changed their focus to work with existing outpatient and not those recently discharged. Despite these challenges, 18 of the target 20 OTs were recruited.

#### *Attrition of Occupational Therapists during the study*

OT attrition took place at several points in the study. Three OTs withdrew from the study prior to recruiting service users to implement GLOW with. Eight OTs did not recruit service users or receive referrals for GLOW during the four month recruitment period.

As can be seen from Figure 9.1, one OT accepted two referrals for service users to use GLOW but did not commence GLOW. A second OT commenced GLOW with two service user participants but could not complete the intervention with either of them.

#### *Recruitment of service user participants*

To identify service users eligible to participate in the study, two approaches were used. OT participants screened service users being discharged from the wards who were under that care of the OT's team and secondly the researcher supported the ward based OTs to screen for participants on the ward. It was planned that each OT would implement GLOW with 2-3 service user participants, therefore twelve OTs not implementing GLOW, represents a large shortfall in the target number of service user participants. The reasons for failure to recruit service user participants varied per OT.

#### *Recruitment of service users by OT participants*

Three of the OT participants who did not receive a referral for GLOW, were not part of a CMHT and did not care co-ordinate clinical caseload, therefore the OTs had no mechanism for screening eligible service users approaching discharge from the acute wards. Two further OTs who were working within CMHTs and had care co-ordination responsibilities, failed to identify eligible service users to recruit. One of the OTs indicated that her team had raised the threshold regarding the criteria for referrals, and this reduced received referrals from the wards.

Finally, two of the OTs were working on specialist teams, early Intervention and assertive community treatment. The OT in the assertive outreach team stated that the service users being

discharge during the time of recruitment had major substance misuse problems and so didn't meet the inclusion criteria for the study. The OT did successfully identify a service user, who initially agreed to take part in the study but later declined to take part in the study. The OT working on the Early Intervention Team identified that at the time of the recruitment service users meeting the inclusion criteria for the study were being transferred to inpatient rehabilitation as there were beds available at that time.

#### *Ward recruitment process*

Recruitment took place on ten wards, in seven Boroughs across two trusts. The arrangements regarding OTs working as part of the ward multidisciplinary team varied for each ward, as did their role on the ward. For example, some OTs spent their time facilitating groups and did not prioritise discharge planning. This had an impact on achieving a systematic approach to screening patients.

One inpatient OT service that was approached with regards to screening service users on the ward appeared concerned that I would compare GLOW to their OT provisions, and some of the OTs demonstrated a lack of knowledge regarding controlled studies. Whilst they agreed to screen for service users, no referrals were received.

Where there were no OTs working within the ward multidisciplinary team, the researcher approached the nursing and medical staff regarding suitable participants. This approach was successful in recruiting one participant to the intervention group and three to the control group. Another eligible participant was identified by the inpatient OT and the researcher, as a referral to an OT participant who worked as a care co-ordinator. However, the OT participant and researcher were unable to contact the eligible service user's care co-ordinator to discuss the study and confirm that the service user wasn't committed to too many current or future research projects that the service user did not mention. This resulted in the OT not being able to implement GLOW with the service user, despite the service users being interested in the study.

Recruitment rates were highest from the wards where there was a full time OT working within the MDT. The researcher visited them weekly at the request of the OTs to ensure they set aside time to look through the ward list. Recruitment rates were low where communication with the ward OTs was not regular and where the researcher did not visit regularly due to time pressure. The researcher called and emailed these ward OTs regularly and the delayed response to these of up to a week, hindered recruitment of service user participants to the study. Three of the wards had vacant OT or part-time agency OT staff, who had limited time to spend on screening patients for the study. The geographical spread of the wards meant the researcher had difficulty getting to each ward regularly and explaining screening criteria and recruitment process.

### *Retention of service user participants*

Table 9.28 presents a summary of the reasons for service user attrition and intervention attrition throughout the study.

**Table 9.28 Summary of reasons for service user and intervention attrition in the study**

Participant	Lost to follow-up	Reason for intervention Attrition
Intervention		
1	Declined	Receive four weeks of intervention only due to clinician's unplanned absence
2		Service user relapse and readmission to hospital
3		Clinician did not carry out intervention
4	Service user relapse	Service user relapse
7		Disengaged from intervention
11		Clinician did not carry out intervention
Control		
14	Declined	
15	Unable to contact	
12	Unable to contact	

### *Analysis of recruitment and retention process*

The recruitment process was analysed and enablers and barriers identified at four levels of the process. The four levels are researcher, organisation, clinician and clinician and service user.

#### **Researcher level**

This study was a standalone research project carried out solely by the Chief Investigator. This had resource implications at every stage of the study. A resource impacting on recruitment into the study was due to the need to expand to a second trust as a result of small numbers of OTs recruited in the first site. With only one researcher for seven boroughs, it became difficult to get to all sites regularly and the researcher had to rely on OTs to screen without weekly meetings, in some sites.

A second resource impacting on recruitment was time limitations. The time designated for recruiting service user participants into the study was six months for one trust and four months for second trust, due to the timeframe of the study. Time delays during the first stage of the study with regards recruiting and running the focus groups which were due to snow and Christmas holidays for staff impacted on the time scale of the study.

### **Organisational level**

As outlined in section 9.4.4 the timing of the study coincided with restructuring and disinvestment of services in one organization. In the context of the study, the OTs' line managers faced high case load numbers of up to 30 per clinician and their role focused on crisis management. This lack of dedicated OT time and time pressures meant that communication was difficult via email and phone and in one case a participant had been identified but difficulty communicating between OT and the service users meant the referral didn't proceed.

A barrier to recruiting Occupational Therapists and to them identifying referrals to implement GLOW with in the first trust was the generic nature of the OTs roles in the psychosis teams. Only one out of the four OTs in psychosis teams had dedicated time to do Occupational therapy interventions.

An enabler of implementing the intervention in one team was that the team leader supported the intervention and could clearly see the benefits of the intervention for the service users. The team leader also identified that the intervention would be beneficial for people changing level of supported accommodation. She asked if the OT could use it with this service user group, but as they were not part of the inclusion criteria this could not take place but is a future consideration of application of intervention.

A team leader of one OT in a psychosis team was also in support of the OT implementing the intervention and was keen to explore the benefits of this intervention for team. This support enabled the OT to participate in the study, but the team did not have any suitable referrals for her.

### **Clinician level**

As can be seen in 9.3.3, at the clinician level, lack of confidence and anxiety about trying a new intervention, was for one OT a barrier to implementing the intervention and therefore participating in the study. The OT did identify that if the whole team was piloting GLOW it would have enabled her to get peer support and to embed the intervention as part of clinical practice. As can be seen in above section regarding organisational context, due to the service pressures, several OTs failed to reply to emails or phone calls on several occasions in the study. This had an impact on recruiting service users to the study, monitoring progress of the intervention, and gathering information regarding current status of service users for follow-up.

### **Service user level**

From Figure 7 we can see that five service users declined to take part in the study. Two of these service users had initially shown interest in taking part in the study. However, the service user changed their minds at the point of arranging to meet the researcher with the OT to further discuss the study. Another of the service users declined to take part as, despite reassurance,

they believed the researcher was working for the job centre and would share all information about their abilities with job centre staff. A fourth participant identified that she had a lot of input from clinical services on the ward and she did not want clinical input in the community. The fifth service user did not explain why they didn't want to participate.

Chapter 9 has presented the results of the pilot study of the GLOW intervention. A discussion of the findings of the pilot study will now be presented in Chapter 10, in addition to the implications of the study for clinicians and researchers.

# Chapter 10 Discussion

## 10.1 Summary of thesis

The aim of this study was to develop and pilot an intervention to improve occupational performance for people with a diagnosed psychotic disorder following discharge from an adult acute mental health ward. Two stages of the Medical Research Council Framework for Developing and Evaluating Complex Interventions were used in this study, developing a complex intervention and feasibility/piloting. The development stage focused on developing a complex intervention to improve occupational performance for people with a diagnosed psychotic disorder following discharge from hospital. This stage was based on best available evidence, gathered using four sub studies. A summary of the sub studies is shown in Table 10.1

**Table 10.1 Summary of sub studies contributing to development of GLOW intervention**

Sub study	Aim	Outcome
Literature Review (Chapter 2)	To identify problems of OP for people with a diagnosed psychotic disorder	Problems with performance skills and knowledge, process skills.  Social and physical environmental barriers  Gender differences in OP  Under occupied  Time spent in passive leisure and sleep  No problems specific to post discharge have been identified.
Focus Groups (Chapter 3)	To identify problems of OP specific to post discharge from hospital	Problems: Barriers to accessing leisure  Environmental barriers, reluctance to being more independent.  Supports: Therapeutic relationship  Slowly picking up daily life  Graded approach, balancing self-care and long term goals
Systematic Review (Chapter 4)	To identify studies of interventions to improve occupational performance	No interventions suitable for use post discharge regarding occupational performance
Identifying the theory base (Chapter 5)	To identify the appropriate theory base for intervention	Model of Human Occupation identified as appropriate theory for the intervention  Intentional Relationship Model identified as theory to reinforce the therapeutic relationship

The literature review identified a knowledge gap regarding identification of the problems and status of occupational performance for people with a diagnosed psychotic disorder following

discharge from hospital. The knowledge gap was addressed by holding focus groups with clinical staff and service users to identify problems and status of OP specific to the period following discharge from hospital. Further knowledge gaps were identified in the systematic review sub study, as no specific interventions for improving OP following discharge were identified. The review also identified 11 studies of interventions to improve occupational performance however; all the interventions require further investigation to demonstrate effectiveness.

The results from the sub studies were synthesised to develop an intervention. A manualised intervention, called GLOW (Graduating Living skills Outside the Ward), and an associated fidelity scale were developed and appropriate outcome measurement tools were identified.

The second element of the MRC framework used in the study was the feasibility and piloting stage. This stage of the study used quantitative and qualitative methods. A quasi experimental controlled study was used to pilot the intervention and establish preliminary evidence of effectiveness. Process evaluation was used to assess the acceptability and feasibility of the intervention, context of the study and recruitment rates.

A total of 18 Occupational Therapists consented to take part in the pilot study and received four hours of training regarding the use of GLOW. Twenty one service user participants were recruited to the study, eleven in the intervention group and ten in the control group. Attrition of OT participants resulted in seven OTs accepting referrals to implement GLOW. Attrition of OT and service user participants resulted in four OTs completing the intervention with five service user participants. Attrition of OTs and service user participants in the study resulted in five service users receiving the intervention as planned.

The intervention was acceptable to the OTs and to the service users. Fidelity to the intervention manual was high for four of the five service users who completed the intervention. The study took place during a time of socio-political and organisational change. This affected state benefits, funding of services, and organisational change. These impacted on the study in several ways. Firstly, disinvestment of services locally reduced the number of OTs in post eligible to take part in the study. Secondly, the disinvestment of services also resulted in increased pressure on community clinical services and the ability of recruited OTs to participate in the study and recruit service users. Finally, the changes in benefits may have affected service user participation in the study in that one service user did not want to participate as he stated he thought the researcher worked for the job centre. One of the OTs implementing GLOW stated she felt the changes to benefits may have increased a service user participant's stress and been a factor in the service user's relapse and re-admission to hospital.



Following intention to treat analysis, the results of the pilot study, indicated that participants in the intervention group, showed a greater improvement on the primary measure when compared to treatment as usual ( $U=13$ ,  $p=.05$ ). Sensitivity analysis of the five service user participants who received GLOW as intended showed a greater improvement on the primary measure than the control group. Four participants in the control groups showed a decrease in score at end point. Areas of improvement in the intervention group on ILSS-SR were personal hygiene, care of personal possessions, food preparation/storage transportation and leisure and community. Participants in the control group increased modestly more than intervention group in the area of health maintenance.

OCAIRS scores increased for three participants in the control group, one participant in the area of habits, one in the area of interests and one in both areas. In contrast six participants receiving GLOW had improved scores on OCAIRS at endpoint. Four of these participants had increased scores for both habits and interests. One participant increased score in habit and one in interest.

## **10.2 Interpretation of results**

This study contributes to the knowledge regarding problems of occupational performance for people with a diagnosed psychotic disorder by reviewing the literature and summarising the current evidence for interventions to improve occupational performance for people with a diagnosed psychotic disorder. This study identified a knowledge gap and subsequently contributed to the knowledge regarding what is known about problems of OP following discharge from hospital, for people with a diagnosed psychotic disorder. An intervention to improve occupational performance following discharge from hospital was developed using best available evidence.

The results of the pilot study indicate that GLOW merits further investigation as an intervention to use in clinical practice for people with a diagnosed psychotic disorder. The study provides further evidence that OTs are unfamiliar and sometimes unconfident with using manualised intervention and with screening for participants. The study highlighted the impact of the reducing number of OTs working in the community and working in specific OT roles on research capacity.

## **10.3 Strengths of Study**

This study has three strengths.

First, the intervention was based on best available evidence. Evidence from service users, clinicians and the literature regarding theoretical knowledge of occupation were drawn together to develop the intervention. This represents an important scientific development within occupationally-oriented research.

Second, there was no contamination between groups in the pilot study. No OTs who received the training regarding GLOW intervention were care co-ordinators for, or involved in the treatment of the participants in the control group. This ensured that there was no contamination between the groups.

Finally, process evaluation was included in the study design. The value of the study has been maximised by both undertaking outcome evaluation and process evaluation, to provide comprehensive results to inform the next phase of the study. The results of the process evaluation can inform further development of the intervention to increase its effectiveness. The study procedures can be enhanced following testing of methods in this pilot study.

#### **10.4 Limitations of study**

This study has five limitations.

First, the quasi-experimental study design has disadvantages due to an absence of random assignment and therefore bias is not minimised as effectively as in a randomised controlled trial.

Second, the target sample size of 30 participants per arm was not achieved. This limits the ability to estimate effect size and inform a power calculation for future studies. The next phase of evaluating the intervention will need to consist of a pilot RCT with a minimum of 30 participants per arm. Recruitment and retention approaches can be informed by the findings from this pilot study.

Third, the assessor was not blind to allocation status. The use of an independent person not involved in recruitment or allocation to complete outcome measurement data from service users would have ensured blindness to arm of intervention and reduced bias in results. Future studies will need to incorporate this data gathering by independent assessor.

Fourth, the control group received treatment as usual rather than an active comparator which would control for non-specific effects such as increased contact time. Therefore change in occupational performance may not be due to the active ingredients of the GLOW intervention. These non-specific effects can be controlled for in future research regarding GLOW, by providing an intervention in addition to treatment as usual with the same frequency as GLOW. For example, include contact with a Support Time Recovery Worker, peer support work or Personal Assistant to participate in leisure and self-care occupations.

Finally, no follow-up assessment was carried out. Follow-up ILSS-SR and OCAIRS measures were planned to be re-administered three months after the intervention, but this was not carried out due to longer than expected recruitment time. Further improvement in occupational performance may occur over time as participants build on achievements made following GLOW intervention.

The collection of follow up data at three and six months following the intervention would allow assessment of sustainability of the changes achieved by the end of intervention. Sustainability of improvements is an important factor in considering the clinical usefulness and the cost effectiveness of an intervention.

## **10.5 Discussion of findings**

The remainder of this chapter discusses each of the findings in detail as well as discussing the challenges faced in this study that impacted on the results. Implications of the study at the level of research and clinical practice are also outlined. Recommendations for carrying out future research in this area are also discussed.

### **10.5.1 Study methods**

The Medical Research Council framework for developing and evaluating complex interventions (Medical Research Council, 2008) was used as a research framework for this study. The framework offers guidance regarding steps in developing a complex intervention effectively, and the study designs required to appropriately assess the effectiveness of the intervention. It offers references regarding study designs and gives examples of studies for all the four stages of the framework. A strength of the framework is its emphasis on the importance of the piloting/feasibility stage to assess procedures and acceptability of a complex intervention, ahead of full evaluation of the intervention. However, the framework does not suggest definitive guidance about the components of a pilot or feasibility study. This is a weakness of the guidance that could be overcome by the inclusion of recommended components of pilot study and rationale for their use. In a review of the literature regarding piloting methods, no clear evidence was found regarding essential components of a pilot study. Therefore guidance from several sources was used to develop the objectives of the pilot study (Lancaster et al., 2004; Saunders et al., 2005). The guidance on developing an intervention manual which was used in this study proved applicable (Carroll & Nuro, 2002). It suggests a staged development of an intervention making it compatible with the MRC Framework. The guidance is recommended for use in developing future versions of GLOW for follow on studies and for other occupationally focused interventions for people with a diagnosed psychotic disorder.

In the process of developing GLOW the researcher identified that consulting service users and clinical staff were key components to the development of the intervention. The focus groups clarified the content and format of the intervention. If studies had been found regarding occupational performance following discharge from hospital, the focus groups would have remained important in clarifying the important aspects of occupational performance to consider during the intervention development. In piloting a complex intervention, comprehensive understanding of process evaluation, intervention fidelity and acceptability were important in formulating effective methods and objectives of the pilot study.

### **10.5.2 Outcome measurement**

The categories within the measure reflect aspects of occupational performance addressed during the GLOW intervention. A disadvantage of the measure is that it does not have normative data against which clinically significant changes can be measured. Ceiling affects were present at baseline for four subscales for 25-31% of those included in analysis, and present at endpoint for five subscales for 18-75% of participants. This indicates the measure may not have detected change sensitively for those participants. The researcher would recommend identifying an alternate measure of OP for use in future studies of GLOW.

Two categories of OCAIRS were used to measure changes in interests and habits, areas not covered by ILSS-SR. The categories of OCAIRS did show change; but, the rating scale does not have published data regarding reliability and validity. A reliable and valid measure of routine and interests is therefore needed to fully assess occupational performance for people with a diagnosed psychotic disorder.

### **10.5.3 Context of study**

From Section 9.3.1 we can see the complexity of the context within which the study took place. These factors regarding the socio-political, organization and team context had a direct impact on each stage of the study. However, research activity is an important component of health services. The Health and Social Care Act 2012 (HMSO, 2012) provides the legal basis for research in the NHS. The act embeds research as a core function of the health service. The intention of the act is to embed a culture of innovation and research at every level within the NHS (HMSO, 2012).

Academic Health Science Centres provide the opportunity to bring researchers and clinical staff together. King's Health Partners, the AHSC participating in this study has been recently formed and this coincided with the disinvestment of clinical services. Despite the disinvestment and uncertainties, healthcare organisations need to consider how to sustain research outputs, in line with its obligations within the Health and Social Care Act.

Therefore research capacity building will need to be an important development in all NHS trusts. A number of approaches have been identified that health care organizations can use to encourage clinicians to participate in research. The approaches are use of an outreach campaign to promote benefits of clinical research, selection of study topics of interest to clinicians and establishment and enforcement of a set of research principles valuing clinicians and patient (Beckett et al., 2011). The approaches also include developing a transparent system of reimbursement for research tasks, provision of technological and technical assistance as needed and promoting a sense of community among clinicians involved in practice based research. The identified strategies could be adopted by NHS organisations with particular

attention to supporting selection of study topics of interest to clinicians to encourage the organisation to feel more equal partners with the research organisation.

The literature regarding clinical staff engaging in research identified an absence of research infrastructure as a barrier to research participation (Golenko, Pager & Holden, 2012; Kahn et al., 2011). A thematic analysis of the role of the organisation in building allied health research capacity (Golenko et al., 2012), identified that a whole organisation approach and support from senior managers were needed to develop a culture of research participation. The study also identified that in health services there is an established organisational structure of research for medical staff, but the same structure of research did not exist for allied health professionals. This lack of an established structure was seen as a barrier to research for allied health professionals. This difference in research structure between professional groups exists in the NHS also. Evolving AHSCs need to review this lack of parity in research structures as part of developing the dual clinical and research role of the organisation.

The study by Golenko and colleagues also identified that streamlining of systems and processes is important in enabling research. The study gave an example of where changes involving amalgamation of some services, within the organization assisted in building a critical mass in some professions and provided links with centres with strong research culture. The development of the CAGs provides the opportunity for all OTs working with people with a psychotic disorder, to be under one management structure and also have the possibility to build a critical mass regarding research planning and participation.

The code of ethics for Occupational Therapists working in the UK stated that Occupational Therapists have a responsibility to participate in research. (College of Occupational Therapists, 2005, 2010). This means that participation in research is part of the core business for Occupational Therapists and no longer an optional activity (Bannigan, Hughes & Booth, 2007). There is no published evidence demonstrating the impact of the addition of research participation to the code ethics for the profession. However, Bannigan and colleagues anecdotally report that this has not resulted in an increase in research generated in occupational therapy (Bannigan et al., 2007). Therefore strategies will need to be developed by NHS organisations to support OTs to participate in research. A formalised structured process of research activities would support OTs at all levels participate in research as part of their everyday practice.

Promoting an appreciation for research-related activities (PARRA) is a process developed to promote a research culture among OT students (du Toit & Wilkinson, 2011). The PARRA process aims to develop research values, habits and role identity to systematically increase research competencies. The approach has potential for use with OTs in clinical practice to develop their active engagement regularly in research activities as part of their job role. For

example, grade specific research competencies could be clearly outlined alongside the tasks expected of them to achieve each competency. This would support a culture of research participation to build and increase capacity for the profession to develop evidence of effectiveness of interventions.

A strategy document published in 2012 describes the Department of Health's commitment to developing clinical academic researchers in nursing, midwifery and allied health professions (Department of Health, 2012). The document emphasises the importance of generating and translating high-quality research at the point of care to facilitate improvement. Furthermore the crucial role of the clinical academic workforce in ensuring diffusion and spread of best practice and innovation is highlighted in the strategy. It defines a clinical academic as a health professional who engages in clinical practice and research, and provides leadership to build a research-led care environment including the development of capacity and capability. To support the development of clinical academic posts in nursing, midwifery and allied health professions the strategy outlined five action points. The five actions are:

1. A national review of these posts currently to inform modelling of future workforce,
2. To secure and sustain clinical academic pathway training,
3. To work with key stakeholders to secure growth in workforce capacity and capability,
4. Accelerate support arrangements to improve access to and participation in training pathways
5. To establish a national development group to lead on embedding clinical academics at the point of care.

The implementation of the action plan provides Occupational Therapy, as an allied health profession, with the support and opportunity to grow a clinical academic workforce and build a culture of research embedded in clinical practice within health service organizations. Additionally OTs need to engage actively with existing national research organisations, for example the Research Centre for Occupation and Mental Health (RCOMH) and the Allied Health Professions Research Network (AHPRN).

#### **10.5.4 Recruitment**

This study encountered barriers to recruitment. The barriers identified were: low number of OTs in community eligible to participate, communication difficulty with OTs and unreliable methods to recruit service user participants.

##### **Barrier One: Occupational Therapist Recruitment**

The total number of OTs eligible to take part in the study across the two trusts was 26, (SLaM 18 and Oxleas, eight). The target recruitment number of OTs in the study was 20, therefore a pool of 26 OTs eligible to take part in the study was a low number of OTs from which to invite participants. Additionally the number of community OTs working with people with psychosis

reduced by four during the study, due to service disinvestment. Three OTs declined to take part in the study. Participation may have been possible for them with organisational support and discussion with regards to approaches to enable them to take part for example, caseload adjustment or negotiating timescale for participation in the study. For example, OT leadership use of influencing skills to highlight the added value to the service user group of piloting an occupationally focused intervention.

This study found that only one service provided interventions implemented by OTs for people following discharge from hospital regarding occupational performance. Five of the OTs in the study worked generically as care co-ordinators with limited or no specific time allocated to OT provision. Only two of them had the opportunity to implement GLOW. The OTs who weren't care co-ordinators or who had specific OT role within their job, reported less challenges to implementing the intervention regarding time pressure. The three OTs in this study who did not receive an appropriate referral to implement GLOW were working full time generically as care co-ordinators and their time use was dominated by dealing with service users' crisis, leaving limited time to identify participants for the study or to implement GLOW. In 1998 the College of Occupational Therapists (Craik et al., 1998) released a position statement on the way forward for research, education and practice in mental health, which states:

*"Occupational therapists should spend the majority of their clinical time working as occupational therapists and not as generalist mental health workers."*  
(p.391)

Despite this statement, there has been a trend for occupational therapists to perform a predominantly generic role when working as part of a Community Mental Health Team (CMHT) and has been an area of discussion over the last three decades, with concerns focusing on OTs potential loss of core skills and professional identity (Craik et al., 1998; Parker, 2001; Pettican & Bryant, 2007; Reeves & Mann, 2004). The care co-ordination role within CPA has also been a recognised professional concern for Community Psychiatric Nurses, who found that the care co-ordination role restricted their ability to use their nursing skills (Simpson, 2005). The experience of OTs and CPNs describe the focus of care co-ordination role on case management and not therapeutic interventions. Whilst CPA has improved community mental health staff's ability to maintain regular contact with service users, it has not produced evidence of improving outcomes for service users (Simpson, Miller & Bowers, 2003). The current focus on the care co-ordination restricts the implementation of specialist clinical interventions to address specific service user needs and attention needs to be given to reviewing the CPA structures to improve outcomes for service users.

In addition to the clinical impact of professionals working in a generic role, the lack of capacity of OTs to focus on occupational focuses interventions will impact on building future evidence regarding interventions to improve occupational performance. Clear guidance and leadership

from OT professional leads and managers is needed to advance research in this area. Influencing skills and political astuteness are key aspects to marketing unique selling points and added value of specific intervention and OTs in leadership positions will need to use such skills effectively influence decisions regarding community interventions (Price & Scowcroft, 2011).

A follow on study to assess the effectiveness of GLOW would require adequate time during the planning stage of the study to seek out and assess number of Trusts needed to recruitment an adequate the number of OTs. An alternative method of carrying out a follow up study to avoid difficulties of recruiting OTs would be to employ several OTs as part of the study, to carry out the intervention. This would lead to efficacy of the intervention but data regarding the impact of the intervention on service users could be adequately assessed provided there were at least 30 service users per arm.

#### Barrier 2: Communication difficulties

Recruitment of service users to the study was negatively affected in two ways by communication difficulties with OT participants and OTs working in the trust who agreed to recruit service user participants from the wards.

A study of methodological challenges faced in an intervention study with older adults, identified that a lack of response to communication was a barrier to recruiting sites (Jackson et al., 2009). The study found that eight of 42 sites did not reply to phone messages and therefore could not take part in the study, thus affecting recruitment to the study. A study examining the factors influencing researcher access to potential study participants identified that clinicians often stated they were too busy to contact service users (Patterson et al., 2010). The study also found that clinicians were concerned that referring service users would increase their workload. This may be a factor in the communication barriers experienced. Similar to this study, Patterson and colleagues identified that substantial structural changes were taking place in some recruitment sites, resulting in research not being seen as a priority (Patterson et al., 2010) Clinicians and managers need to recognise engagement in research as part of their role to ensure they contribute to research and are not barriers to developing the evidence for their profession. Due to the paucity of evidence of effectiveness regarding interventions to improve occupational performance, the OT profession needs to prioritise research to improve this lack of evidence base. As outlined previously, PARRA (du Toit & Wilkinson, 2011), provides a suitable model to embed research tasks within everyday activities of clinical staff.

#### Barrier 3: Unreliable methods of recruiting service users

Eight OT participants did not have any appropriate referrals for GLOW intervention. As identified above, communication with the OTs hindered recruitment of service users. A further explanation for the limitations in recruitment is the level of support offered by the researcher. The inclusion criteria for service user participants were explained by the researcher as part of the training



regarding GLOW. Examples of clinical indicators in addition to the details outlined in the screening tool were given and discussed. However, the researcher had limited time to regularly visit and go through the inclusion criteria with each OT involved in recruiting. Therefore some sites received more regular support than others to identify service users for the study. Therefore it is unknown how many service users were screened and deemed unsuitable by the OTs. The reasons for any decision regarding exclusion are also unknown. In this study it is unknown whether the OTs felt confident in explaining the study to service users. This may have been a barrier to recruiting service users. Additionally, the OTs may have interpreted the inclusion criteria differently and therefore have excluded potentially appropriate participants. All of these stages of recruitment merit more systematic investigation.

The role of the OT in each ward differed, for example some OTs facilitated groups on a daily basis, which limited time for discharge planning. This indicates that the OTs are not systematically involved in discharge planning which affects the routine identification of occupational needs on discharge.

Barriers to clinicians recruiting service users to clinical research studies have been identified. The barriers were related to the clinicians' misconceptions of randomised controlled trials including misunderstanding the components of the trial arms (Howard et al., 2009; Patterson et al., 2010). The clinicians' variable interpretation of eligibility criteria was also identified in the studies by Howard et al and Patterson et al. Being over protective of service users was also identified as a barrier to recruitment (Howard et al., 2009). The barriers identified may explain the poor recruitment rates of some of the recruiting clinicians on this study.

The barriers to OTs screening and approaching service users regarding participation in research requires further investigation during the planning phase of a follow on study regarding GLOW, in order to develop a strategy to increase OTs participation in research.

The MRC framework emphasises the importance of a pilot study in testing recruitment strategies, but does not provide further detail, therefore more guidance on testing recruitment as part of pilot study, needs to be developed. The literature, regarding strategies to enhance recruitment of participants into mental health research studies, focuses on four levels of the research process. The levels are: the planning phase of a research study, the researcher, clinician and research participant.

During the planning of design and methods of a research study, early considerations of recruitment and retention techniques is important for successful inclusion criteria and budget considerations required to recruit target sample size (Patel, Doku & Tennakoon, 2003). Additionally, Patel and colleagues identified that consideration of potential recruitment sites is also important in the planning stage of a study. The authors outline that recruitment rates may

be affected in over researched sites whereas staff in less researched sites may be more receptive to research. These approaches are relevant to planning future GLOW studies as careful consideration of study sites is needed to ensure recruitment targets are met and contextual factors minimised. For example, less researched trusts may have more vested interest in studies to enable them to improve their research profile. NHS services in London are oversubscribed due to large population, however, NHS Trusts outside London may be less subscribed and have capacity to engage with service users for long. A study to further assess the effectiveness of GLOW would benefit from careful consideration of recruitment and retention techniques and identification of research sites, during the planning phase of the study to maximise recruitment.

Strategies that the researcher can use throughout stages of the study to enhance recruitment have been identified. The researcher's identification of suitable key gatekeepers to service user participant has been identified as an important component of setting up local recruitment processes (Patterson, Mairs & Borschmann, 2011). Specifically, consideration of the gatekeepers' authority to make decisions and ability to facilitate necessary action, regarding recruitment has been identified as important. The identification of important gatekeepers in positions of authority is also key to the successful access to teams for recruitment. Building a strong working alliance with gatekeepers such as clinicians by having regular face to face contact with them (Patel et al., 2003; Patterson et al., 2011). Additionally, the researcher needs to acknowledge and address concerns from clinical staff about the vulnerability of research participants, at the outset of recruitment (Howard et al., 2009).

Prior to recruitment starting the researcher can enhance recruitment by clearly explaining the reason for research, the nature of control arm, and eligibility criteria (Howard et al., 2009). To effectively get results from requests from clinicians, making specific, measurable, achievable, realistic, and time limited (SMART) requests is recommended (Patterson et al., 2011). The use of SMART goals is a time effective way of progressing recruitment within clinical teams, as the clinician is clear about what is expected to them, and knows that meeting this goal means less disruption to their clinical time by the researcher needing to further prompt the clinician to act on the requests.

At the level of the service user, a systematic review of controlled trials on recruitment methods identified that monetary incentives, using a known treatment rather than a placebo design in the control group and making trials materials culturally sensitive, all increased recruitment (Watson & Torgerson, 2006). The study identified that blinding decreased recruitment rates. None of the included studies had participants with mental health problems. A review of strategies to increase recruitment of study participants who have a diagnosed mental illness with mental health problems would be helpful in developing effective recruitment strategies and support participants to consider taking part in research.

In summary, to enhance recruitment of participants into studies a range of strategies are required at various stages of the research process. Table 10.2 summarises the strategies examined in this section.

**Table 10.2 Strategies to increase recruitment into research studies**

Stage of Research	Strategy
Planning study design and methods	Consideration of recruitment and retention techniques in deciding inclusion criteria and budget of study
	Consideration of potential research sites to avoid potential recruitment problems in over researched sites.
Setting up local recruitment processes	Identification of suitable gatekeepers with authority to make decision and facilitate necessary actions to recruit service user participants
Introducing research to clinical teams	Provide clear explanation of: rationale for research project nature of control arm eligibility criteria
Requesting actions from clinicians	Make specific, measurable, achievable, realistic and time limited (SMART) requests.

#### **10.5.5 Effectiveness of the Intervention**

Results of pilot studies regarding effectiveness of interventions need to be interpreted cautiously. The small sample size of 21 participants in this study indicates that an effect size cannot be calculated for the intervention. However, there was a significant difference in change scores for the intervention group when compared to the control group. This is consistent with the individual changes identified in the case series present in Section 9.3.1. Overall, there is preliminary evidence of effectiveness of the GLOW intervention indicating it merits further evaluation.

A future study to investigate effectiveness of GLOW would need to consider what intervention the control group receive to ensure this non-specific effect of additional staff contact is eliminated.

#### **10.5.6 Acceptability of the intervention**

The results of the questionnaire identified that the clinical staff and service users found the intervention to be acceptable to them. As outlined in Section 9.3.2, however, one of the OTs indicated during the semi structured interview regarding implementing GLOW, that they were tentative about implementing the high intensity engagement for first four weeks. The OT felt it maybe too intrusive for the service user. The OT did not discuss this with the service user involved.

In a study of implementation of a manualised intervention in older adults by OTs (Van't Leven et al., 2012) concerns regarding level of intensity of intervention were also raised. The OTs in that study indicated that weekly visits may overload the patient. Results of previous studies of this intervention for older adults found the intervention to be effect and cost-effective, indicating that the intervention was acceptable to the service users. It is interesting to note that in both cases the intensity of the intervention had not been raised as a concern by the service user but by the clinician only. This could indicate reluctance of OT to have an open dialogue regarding how the service user felt about frequency of visits. This could indicate that the clinicians feel protective towards their service users. It could also be factors within the OT regarding their concerns about committing to weekly visits. The issue implementing manualised interventions to improve OP requires further examination.

A study investigating recruitment difficulties in an RCT for people with severe mental health problems, identified a similar finding (Howard et al., 2009). The study identified that clinical staff were overprotective of the service users and focused on their own perception of the service users' needs, such as protecting them from perceived stress of taking part in the study. To guard against clinical staff becoming a barrier to service user participation in intervention studies, their over protective approach needs to be discussed at a team level and between clinicians and researchers at the planning stage of a study. In this way clinical staff will have the opportunity to address their concerns regarding intensity of an intervention and suitability of a study for service users, by discussing the inclusion criteria and rationale for the intervention.

One initiative locally, named "Consent to consent" aims to reduce the recruitment burden of staff by establishing a database of service users in the trust who are agreeable to be contacted regarding research. This could reduce the impact of over protectiveness of staff as barrier to inviting service users to take part in research. However, the clinician will need to confirm with the researcher that the service user is well enough to take part in a study, this could potentially cause staff to remain over protective by saying the participant is not well enough to take part. Clear guidance will need to in place regarding criteria for excluding on the grounds on capacity to consent or status of mental health symptoms.

#### **10.5.7 Fidelity to the intervention manual**

Assessment of fidelity to the intervention manual showed that five components were not adhered to by all four OTs implementing the intervention. Two service user participants did not receive weekly visits as planned. The OT had identified that the service users did not require the level of intensity due to other support mechanism being in place. This indicates the need for intervention manual to be amended to outline that the service user is to be offered weekly visits and to clearly document where the service user agreed that they did not require weekly visits from the OT following discharge from hospital.

Despite the manual outlining the tasks the OTs were required to carry out at baseline and at endpoint as part of the clinical intervention. Two measures were not re-administered. Future training regarding GLOW will need to include a greater emphasis on rationale and mandatory nature of processes involved.

Two of the therapeutic modes were not used by all the OTs. Additionally, the OTs talked less about the Intentional Relationship Model components of the intervention, than other components. This could indicate that the OTs have not fully integrated the concept of therapeutic modes into their clinical reasoning.

Two of the OTs, who were working generically as care co-ordinators found it a challenge to deliver the sessions as frequently as required. In a study regarding implementation of an OT intervention manual for people with dementia, the OTs similarly identified that their regular work did not leave enough time to spend on the intervention (Van't Leven et al., 2012). The OTs in the study additionally identified that they were not used to carrying out such a comprehensive intervention at home and had difficulty prioritising the intensive intervention time.

This highlights the challenge for clinicians in prioritising time for a new clinical task within existing working practices. This challenge could be addressed in future studies by examining OTs existing caseloads with their managers and ensuring the time required for new intervention is adjusted for during the study. Another approach would be for a service to use the intervention being studied, with all new referrals.

Manualised interventions are not widely used by Occupational Therapists in clinical practice and are viewed as difficult to apply (Blanche et al., 2011). Unfamiliarity with using manualised intervention in clinical practice may have been a barrier to fidelity to the intervention. Therefore the OTs in this study may have not referred to the intervention manual as regularly as needed, to adhere to the content as they are unfamiliar with referring to intervention manuals. Another explanation for the lack of fidelity could be lack of attention to the manual as the intervention was nearing completion. Finally, it may be that the OTs did not pay close attention to the end of the training session which covered tasks required of them at the end of the low intensity 6 week component. Future training regarding use of GLOW will need to include more rigorous methods of ensuring the OTs fully understand GLOW procedures, by asking the OTs to present case studies of potential use of GLOW. It could also indicate the lack of awareness regarding the role of manualised interventions in evidence based practice.

A barrier to fidelity of the intervention could be due to the level of support offered by the researcher regarding intervention implementation. The researcher had planned to offer fortnightly phone or face to face supervision with the OTs during the implementation of the intervention. However, due to the additional time required to increase recruitment of OTs and

service users into the study, the researcher could not offer this level of support. Instead, the researcher agreed to contact the OTs every two – three weeks by phone or email, to discuss how the implementation is going and for the OTs to phone the researcher in between with any questions.

#### *Changes to fidelity testing*

The results of the fidelity testing in this study indicate that standardisation of the training and testing of OT acquisition of intervention skills would be beneficial to determine if the OTs fully understood, retained and applied all the content of the training. This would be particularly useful in relation to training delivered and OTs learning regarding Intentional Relationship Model, which OTs talked about least during the semi structured interviews. More detailed assessment of which aspects of the intervention are being implemented would also be beneficial and could be monitored by pre-booking regular supervision sessions with the researcher throughout the intervention. Regular supervision would also prevent drift in intervention skills over time (Bellg et al., 2004).

Bellg and colleagues suggest treatment fidelity strategies for improving delivery of the intervention and they suggest monitoring participants' perceptions of nonspecific treatment effects across both groups. This would enable the researcher to control for clinician differences in the next phase of the study.

Participants in this study were asked what elements of the intervention they received, in addition to which component work best and least well, and for what reasons. However, the service users' comprehension of information they received was not assessed to test receipt of the intervention. This could be done by asking service user participants what they have learnt about their own occupation following the intervention. Assessing the receipt of intervention in this way enables monitoring and improving the ability of the participant to understand and develop treatment related changes (Bellg et al., 2004).

More in-depth fidelity testing is needed in the next phase of study to ensure accurate assessment of effectiveness of the intervention. Comprehensive guidance was found in the literature regarding strategies to improve treatment fidelity as well as fidelity assessment (Bellg et al., 2004). The researcher recommends its use in future studies regarding GLOW and other complex interventions in health services.

#### **10.5.8 Current literature regarding occupational performance**

Since the completion of the systematic and literature reviews regarding OP for people with a diagnosed psychotic disorder and completion of the pilot study, new systematic reviews and studies have been published that relate to the topic. The results of these sub studies were updated by rerunning the searches used in systematic review and literature review. A further

three systematic reviews and three intervention studies were found. Three new studies of occupational performance have been also identified.

All three systematic reviews focused on interventions to improve performance of defined categories of occupations for adults with mental health problems. Table 10.3 presents a summary of these reviews.

**Table 10.3 Summary of recently published systematic reviews**

Author	Focus of review	Population	Inclusion criteria	Results
Gibson, D'Aimico, Jaffe & Arbesman, 2011	Occupational Therapy interventions for recovery in areas of Community Integration and Normative roles life roles	Adults with Serious mental Illness	evidence-based medicine, level of evidence was used: studies of I-III were included. Interventions focused on instrumental activities of daily living, education and work	52 studies included. Results: Moderate to strong evidence for the effectiveness of social skills training and Individual Placement and Support, moderate evidence for life skills, and Instrumental ADL training and supported education, neurocognitive training paired with skills training in the areas of work, social participation and Instrumental ADLs.
Arbesman & Logsdon, 2011	Occupational Therapy Interventions for Employment and education	Adults with Serious mental Illness	Evidence-based medicine, level of evidence was used: Studies of I-III were included. Interventions to improve or maintain paid or unpaid employment: Volunteering, home management, child care and education	46 studies included. Results: Strong evidence for supported employment, supported education,
Bullock & Bannigan, 2011	Effectiveness of activity based group work in community MH	Adults with anxiety, depression, bipolar and psychosis	Group interventions consisting of "doing" activities	Three studies found activity group more effective than verbal groups

None of the systematic reviews identified interventions specifically focused on improving occupational performance following discharge from hospital. Two of the reviews used the scope of occupational therapy practice, as outlined by the American Occupational Therapy Association (AOTA), as the inclusion criteria for interventions for adults with serious mental illness.

(Arbesman & Logsdon, 2011; Gibson et al., 2011). Using the scope of practice of a profession is a different approach than was used in the systematic review in Chapter 4, which looked at interventions focusing on a specific problem and not what clinical staff may implement the intervention. The same two reviews also followed the system for grading the level of evidence of studies that AOTA uses, this system grades studies by methodology used and not by quality, therefore the reviews have not accurately assessed the significance of the results of the studies. The third review focuses on the effectiveness of activity-based group work in mental health and concluded that there is a lack of rigorous scientific research to support practice of activity-based group work (Bullock & Bannigan, 2011). The reviews did not identify further studies meeting the inclusion criteria for systematic review in Chapter 4.

Three new studies of interventions to improve occupational performance have been identified, and these studies are summarised in Table 10.4

**Table 10.4 Summary of recent interventions to improve occupational performance**

Author	Intervention	Study design	Sample Size	Study population	Outcome	Results
Edgelow & Krupa, 2011	Action Over Inertia: To increase time-use	RCT	24	Adults with schizophrenia schizoaffective	Profiles of Occupational Engagement for People with schizophrenia (POES) 24 hour time diaries	$d = .86$ in favour of intervention for reduced sleep time
Katz & Keren, 2011	Occupational Goal Intervention versus Frontal Executive Program versus Activity Training Approach	Controlled trial	18	Adults with schizophrenia	Routine Task Inventory-Expanded (RTI-E) Activity Card Sort (ACS)	ACS: $d = .78$ in favour of OGA
Lindström et al, 2012	Everyday Life Rehabilitation	Pre-test post-test	17	Adults with schizophrenia and schizoaffective	Goal Attainment Scaling (GAS) Assessment of Motor and Process Skills (AMPS)	$*d = 3.75$ in favour of the intervention

None of the recent interventions were aimed at improve occupational performance following discharge from hospital. All the outcome measures in the studies had been used in studies identified in the systematic review outline in Chapter 4.

The results of the updated systematic review did not identify new information that could have informed the study, if they were published earlier. The results of the studies do not impact on plans for future research regarding GLOW.



An updated literature review identified five recent studies regarding occupational performance and psychosis. Table 10.5 presents a summary of these studies.

**Table 10.5 Summary of recent studies of OP and psychosis**

Study	Sample	Method	Aims
Argentzell, Håkansson and Eklund, 2012	12 unemployed adults with severe mental health problems (10 with psychosis)	Semi-structured interviews	To examine meaning in every day occupations
Brown, 2011	Five adults diagnosed with a psychotic disorder in previous five years.	Semi-structured interviews	To understand how psychosis has affected the participants OP
Eklund, Hermansson and Håkansson, 2012	Ten adults with schizophrenia	Semi-structured interviews	To understand what brings meaning to life for participants
Lee et al , 2011	625 adults with mental health problems, (223 with psychosis)	Retrospective analysis of data from MOHOST measure	To characterise the occupational profiles of service users
Killaspy et al, 2013	67 adults with psychosis	Cross-sectional survey	To investigate change in social inclusion after development of psychosis and factors associated with this.

One study developed occupational profiles for people with a diagnosed psychotic disorder using retrospective MOHOST scores of 625 users of mental health services in two NHS trusts (Lee et al., 2011). The results outlined that the mean scores for MOHOST subscale scores in categories as set out in Payment by Results clinical clusters for people with mental health problems: first episode psychosis, recurrent psychosis (low symptoms), ongoing or recurrent psychosis (high disability) and ongoing or recurrent psychosis (high symptom and disability). The ongoing recurrent psychosis cluster (high disability) reflects most closely the status of the participants in the GLOW study. Table 10.6 presents a comparison the mean subscale scores for the participants of the study by Lee and colleagues (2011), who were in the recurrent psychosis (high disability) cluster, and the baseline participant mean scores for GLOW participants.

**Table 10.6 MOHOST difference in mean subscale scores for GLOW participants and national cluster score**

<b>MOHOST subscale</b>	<b>Ongoing or recurrent psychosis (high disability) cluster sample (n=75) Mean score</b>	<b>Baseline scores GLOW participants (n= 5)</b>
Volition	2.4	2.82
Habituation	2.18	2.75
Communication and interaction skills	2.76	3.21
Process Skills	2.5	3.00
Motor Skills	3.04	3.61
Environment	2.78	2.75

From Table 10.5 we can see that, with the exception of process skills, the mean scores for all subscales fall within the same numeric value between one and four, the values for this measure. This supports the use of GLOW as an appropriate intervention for service users within the ongoing or recurrent psychosis clusters with and therefore has potential for use within payment by results for this cluster group.

A study of people who were diagnosed with a psychotic disorder within the previous 5 years, reported that looking back at early life, they experienced difficulties with occupational performance, further indicating the disruption to development of skills caused by the illness as described in Section 2.3.1 (Brown, 2011). The same study identified that the participants learned how psychosis affected their ability to do familiar tasks (Brown, 2011). The participants also described how they graded everyday occupations as their mental health improved. The study recommends that interventions to improve occupational performance are collaboratively implemented with service users, offering options and suggestions. The study identified that “learning through doing” is an important aspect of improving occupational performance. This study re-affirms GLOW’s approach to improving occupational performance through “doing occupations” in the participants home and community and through use of a collaborative approach. The study re-affirms the results found in the focus groups and literature used to inform the intervention.

A study aiming to explore meaning in life as described by people with schizophrenia identified that having an everyday life that functions well was important (Eklund, Hermansson & Håkansson, 2012). The study also identified that taking part in activities of interest were important components of meaning in life. A study of the experience of meaning found in daily occupations for unemployed adults with severe mental health problems also found having a balance between different meaningful occupations helped them have control over their mental

illness (Argentzell, Håkansson & Eklund, 2012). The study also identified that feeling competent helped that to feel accepted by society, and that having a daily and weekly routine and being creative was meaningful to them. The results of these two studies reaffirm the importance of understanding one's own occupation, leisure and a daily routine as part of the GLOW intervention.

A study of the impact of psychosis on social inclusion identified that two domains of social inclusion were found to change over time following development of a psychotic disorder, productivity and social integration (Killaspy et al., 2013). The study identified that the longer the person had a psychotic disorder, the greater decline in social integration and productivity, this confirms the need to provide interventions to improve occupational performance, such as GLOW in a timely manner, to prevent long term disability. This supports the rationale for providing GLOW intervention following discharge from hospital. The results of this study also indicate the need to address productive occupations in a timely manner also, to prevent long term difficulties in this area of occupation. Therefore the revised version of GLOW will also focus on productive occupations in addition to self-care and leisure.

#### *Current mental health policy on Recovery*

A recent policy objectives recently set by the government is that more people with mental health problems will recover (Lambert et al., 2007). The objective outlines that more people with mental health problems will have a greater ability to manage their own lives, have stronger social relationships, a greater sense of purpose, the skills they need for living and working, improved chances in education. Therefore services for people with mental health problems are required to be recovery orientated. Personal recovery has been defined as

*"a way of living a satisfying, hopeful and contributing life even with limitations caused by illness" (Anthony, 1993, p.18)*

A conceptual framework for personal recovery has been developed and comprising of five categories: connectedness, hope and optimism about the future, identity, meaning of life and empowerment (Leamy et al., 2011). As reported in Section 1.2, people with mental health problems have identified that leisure and play enable them to become hopeful for the future (Davidson et al., 2001). Leisure and play also enabled rediscovery of areas of strength and competence (Davidson, 2003) which are components of identity and empowerment. This demonstrates the importance of "doing" to support personal recovery.

Current recovery orientated interventions focus on conceptualising and establishing goals for the future, for example, using Wellness Recovery Action Plans (Copeland, 2001). However, little attention is paid to translating the goals into action. Therefore there is an evidence gap regarding the operationalisation of recovery. Given this context, the relevance of GLOW as a suitable intervention within recovery orientated practice needs to be examined.

Many shared values between recovery and occupational therapy have been identified in the literature (Davidson, 2007; Gruhl, 2005). Davidson (2007), identifies that action theory should be applied in recovery practice and that occupational therapy and occupational science share this approach of viewing a person as being their own agents of change through experience. Gruhl (2005) identified shared assumptions regarding recovery and occupational therapy, further indicating that occupational therapy can be viewed as a recovery orientated profession.

A recent study regarding community participation and the process of recovery for people with diagnosed mental health problems identified key factors in supporting their recovery (Fieldhouse, 2012). The participants identified ten factors which the authors summarised as “scaffolding”, a process of skill acquisition through facilitated temporary support to enable personal agency once “scaffolding” is removed (Fieldhouse, 2012). Several of the components overlap with GLOW as outlined in Table 10.7.

**Table 10.7 Similarities between “scaffolding” components and GLOW**

<b>Scaffolding Components</b>	<b>Related GLOW Component</b>
Identifying personal investment in change: Eliciting Goals	MOHOST, REIS-SF and Interest Checklist
Grading and pacing	Activity grading
Therapeutic use of self	Intentional Relationship Model
Person-centred Care planning	Use of MOHOST, REIS-SF and interest checklist to plan intervention
Community Mapping	Community environmental analysis
Being a “travel companion”	Doing alongside the service user
Creating affirmative environments	Graded approach
Positive risk management	
Harnessing social capital	Analysis of local environment to highlight supportive social environments.
Advocacy and interagency lobbying	Advocating mode of IRM

From Table 10.3 we can see that nine of the ten components of scaffolding are addressed by GLOW indicating that GLOW is a recovery orientated intervention.

GLOW provides service users with the opportunity to actively participate in negotiating and engaging in meaningful occupations. In addition to GLOW supporting service users to

understand their own occupational performance and to make choices regarding occupation, the aim of the intervention fits within the recovery practice framework (Le Boutillier et al., 2011). This framework outlines the components of recovery focused practice and includes elements relating to working relationship, support for personally defined recovery, promoting citizenship, and organisational commitment. GLOW can be seen as contributing to these elements by working in partnership with service users to identify personally meaningful goals relating to self-care and leisure. The focus on accessing meaningful occupations in the community contributes to promoting citizenship for the service users.

A recent report by the Schizophrenia commission outlines the importance of addressing the social component of mental illness and identifies OT amongst the staff group that have a crucial role in addressing this (The Schizophrenia Commission, 2012). The report however, fails to address what interventions should be used to address this social component. GLOW can provide a valuable approach to supporting service users to consider their social networks within community opportunities that promote the building of social support.

Overall, GLOW can be viewed as a recovery orientated intervention and adds to the body of knowledge regarding recovery orientated services aimed at improving self determination regarding self-care and leisure.

## **10.6 Modifications to GLOW**

The process of piloting of the intervention has highlighted improvements that can be made to the intervention manual. As outlined in section 10.5.8 the intervention would benefit from the addition of productive occupations to ensure needs in this area are addressed in a timely manner to prevent long term difficulties with productive occupations. A more detailed description of the components would support the OTs using the manual to more fully understand the components. The detailed description will need to include information regarding unique and essential components for each level of intensity. A clear summary of mandatory components and optional components will be outlined. More detailed description would decrease possibility that the OTs may assume that they know what they mean, rather than actually fully understanding the definitions. On the other hand, care must be taken to ensure that the GLOW manual does not become too long or detailed to read and understand, creating an implementation barrier. Prompt sheets will also be included in the intervention manual for use by the OTs during each session to improve fidelity. Case studies can now be added to the manual following this pilot study, to illuminate the intervention process. The next study regarding GLOW will require a larger sample size of at least 30 per arm to increase accuracy of measurement of effectiveness of the intervention. The next study would benefit from being a pilot randomised controlled trial, which remains at the second stage of the MRC framework. Following initial piloting of the intervention and training in use of the intervention manual, the manual remains a stage I manual for use within a pilot RCT (Carroll & Nuro, 2002).

### *Changes to training regarding implementation of GLOW*

From the results of the study it is clear that the OTs implementing GLOW did not attend to all the components of the intervention, for example re-administering REIS-SF and Interest Checklist. An increase in the interactive component of the training regarding components of GLOW would support more effective learning of the components by increasing familiarity with the format for their use in GLOW. The interactive components will consist of case studies which the OTs can discuss how GLOW would apply, as well as asking participants to share their understanding of the components of GLOW. The component of GLOW regarding supporting service users to increase their self knowledge of occupational performance requires more detail discussion during the training. This will allow the OTs to practice and discuss with each other how they might explain the components of occupational performance to the service users.

In addition to increasing the detail and learner participation in the training, assessment of learning will take place at the end of the training session. A self assessment tool regarding use of IRM has been developed by the author of the model, Dr. Taylor, and the researcher will request permission for this to be used as part of the assessment tools regarding GLOW training. The participants will be asked to complete a questionnaire asking them to explain components of GLOW, in addition to how they might explain aspects of occupational performance to service users.

## **10.7 Implications for clinical practice**

This study adds to the body of knowledge regarding what is known about occupational performance for people with a diagnosed psychotic disorder in addition to specific knowledge regarding occupational performance following discharge from hospital. The literature review synthesised what is known regarding occupational performance for people with a diagnosed psychotic disorder. This summary of what is now known is of clinical use to OTs and other professionals to inform their service structures, assessment and intervention processes with people with a diagnosed mental health problem.

New knowledge has been generated from analysis of focus groups, regarding problems of occupational performance following discharge from hospital. This new knowledge is of clinical use to OTs and other professionals when planning services regarding processes to support discharge from hospital.

The results of this study indicate that GLOW, the intervention developed, is potentially useful as an intervention in clinical practice for people with a diagnosed psychotic disorder. GLOW can be viewed as recovery-orientated intervention, contributing to an individuals' personal recovery by enabling active participation in occupations at home and in the community and supporting an increase in self knowledge of OP. The intervention was intended for use for people with a

diagnosed psychotic disorder following discharge from hospital, however, one of the team leaders of an OT participant, indicated that it would be useful for people moving between levels of supported accommodation also. This has resulted in two OTs, one of whom took part in the study, planning to use GLOW with people with psychosis following discharge and following moving to more independent accommodation in new neighbourhoods within SLaM Psychosis CAG. Since completion of the study and presenting the study at three conferences, the researcher has received expressions of interest to use GLOW within Re-ablement, rehabilitation and forensic services to support service user transition from hospital to home or to a lower level of supported accommodation. Furthermore, a team in a separate trust to those participating in the study has commenced a new service for people with mental health problems post-discharge from hospital and are implementing GLOW within routine practice. This indicates that GLOW has use for many transitional stages for service users, within clinical services and their lives in the community. Feedback from the OTs regarding use of GLOW will continue to be collected by the OTs to further develop GLOW.

Despite evidence from this study and previous studies, that OTs are unfamiliar with using manualised intervention in clinical practice, the interest from clinicians and managers in implementing GLOW indicates a positive view of manualised interventions. Regular opportunities to discuss the benefits and processes of using manualised interventions in clinical practice are required to further create a culture of using manualised interventions.

The study highlights the lack of experience of OTs in participating in research tasks, for example taking part in focus groups and screening for suitable participants. A formal structure format such as PARRA (du Toit & Wilkinson, 2011), can be recommended to increase research competencies and embed a culture of research participation within OT practice.

The study highlighted the reducing number of OTs working in the community and working in specific OT roles, which creates challenges for evaluating the effectiveness of the intervention, in a future larger study. In order to support OTs in restricted clinical roles within the CPA to gain protected time to implement occupationally focused interventions, the professional lead OTs require influencing skills and political astuteness to present the benefits of this way of working to management staff.

## **10.8 Implications for research**

This study adds to the body of knowledge regarding what is known about interventions to improve occupational performance for people with a diagnosed psychotic disorder, this can inform future intervention research in this area. This study identified a knowledge gap regarding occupational performance following discharge from hospital. The focus groups have generated new knowledge in this area, and can be used as a foundation for further studies in this area.

Results of the systematic review provides a benchmark for current knowledge regarding strengths and weaknesses of existing interventions, this knowledge can inform researchers regarding interventions to further investigate or identify a gap in interventions developed. This new knowledge also provides valuable information regarding outcome measures that can inform future research in this area. The lack of consensus regarding outcome measures may have an impact on clinical services in the future. The inclusion of interventions to improve OP for people with a diagnosed psychotic disorder in the NICE guidance is of increasing importance. This is due to recent changes in commissioning whereby GPs, who may have little knowledge of mental health needs may rely on NICE guidance to commission clinical services. Intervention studies therefore need to be a priority for research in this area. The importance of use of same outcome measure to enable aggregation of results of intervention studies regarding improving OP for people with psychosis is therefore a priority for research in this area also.

The researcher recommends a series of large epidemiological studies reporting on levels of occupational performance at discharge, three and six months post discharge to gain a more comprehensive understand of occupational performance following discharge from hospital. This would also enable further understanding of the decrease in scores of participants' scores in the control group. This would require routine assessment of occupational performance using valid and reliable tool by community staff. An anonymised research databases could be used to collate the data over time.

Further research is required to identify or develop a measure of occupational performance that can be used to measure change in a reliable and valid way, included measuring clinical significance.

This study confirmed that GLOW has shown preliminary evidence of effectiveness, in addition to being acceptable to the clinicians and service users participating in the study. This indicates that GLOW warrants further study to evaluate its effectiveness. The study will need to use a larger sample size and use a randomised controlled study design. Economic evaluation of the intervention is also an important component of the next stage of study for the intervention. The researcher recommends the inclusion of a measure of recovery and quality of life in addition to measures of occupational performance. Three and six month follow-up of participants will be important in determining sustained effectiveness of the intervention. Consideration of intervention included in the control group instead of treatment as usual will reduce the nonspecific effects in the intervention. A full assessment of potential sites with OTs available to participate and level of support available on each site will need to be carried out prior to developing study protocol.



## 10.9 Conclusions

This study contributes to the knowledge regarding occupational performance for people with a diagnosed psychotic disorder in six ways. Firstly, the literature regarding occupational performance for people with a diagnosed psychotic disorder has been synthesised to create a benchmark regarding current knowledge. Secondly a systematic review also created a benchmark of what is known regarding interventions to improve occupational performance. Additionally it identified that more evidence is needed regarding interventions to improve occupational performance and highlighted the gaps in knowledge regarding suitable outcome measures. Thirdly, new knowledge has been generated from focus groups regarding problems of occupational performance following discharge from hospital.

Fourthly, a new intervention has been developed to meet an identified need to enable improvement in occupational performance following discharge from hospital for people with a diagnosed psychotic disorder. An intervention GLOW has been developed for use by Occupational Therapists. The fifth way this study contributes to the knowledge regarding occupational performance for people with a diagnosed psychotic disorder is that the intervention has been piloted. The results of the pilot study demonstrate that GLOW warrants further investigation to assess effectiveness. Refinement of the intervention, training and outcomes of the study are needed prior to the next study.

Finally, barriers to recruitment of OTs and service user participants were encountered in this study. This indicates that a reduction in numbers of OTs working in the community and OTs working generically are barriers that need to be addressed to enable research of occupationally focused intervention.

The intervention developed in this study, GLOW has been recognised by clinicians and service managers as having potential clinical use during many transitional stages of service users' journey through clinical services. This provides the opportunity to further test the intervention in many clinical settings and expand the use of manualised interventions to improve occupational performance.

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## Appendix 1



### **National Research Ethics Service**

**South East London Research Ethics Committee (REC) 4**  
(Formerly known as The Joint South London and Maudsley and Institute of Psychiatry  
Research Ethics Committee)  
1st Floor, Camberwell Building  
94 Denmark Hill  
London  
SE5 9RS

Telephone: 020 3299 5033  
Facsimile: 020 3299 5085

07 October 2010

Miss Mary Birken  
Institute of Psychiatry, Box PO29  
De Crespigny Park,  
London,  
SE5 8AF

Dear Miss Birken

**Study Title:** **An investigation of the effectiveness of interventions to enhance the occupational performance of people with psychotic conditions, following discharge from an acute inpatient mental health ward**

**REC reference number:** 10/H0807/69

Thank you for your letter of 28 September 2010, responding to the Committee's request for further information on the above research and for submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Conditions of the favourable opinion**

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research

This Research Ethics Committee is an advisory committee to London Strategic Health Authority  
The National Research Ethics Service (NRES) represents the NRES Directorate within  
the National Patient Safety Agency and Research Ethics Committees in England

governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Investigator CV	1	07 July 2010
Protocol	1	06 July 2010
Protocol	2	13 September 2010
CV: Dr Mike Slade	1	07 July 2010
Letter of invitation to participant (standard of care)	1	07 July 2010
Confirmation KCL Insurance Policy Number	1	05 July 2010
REC application	3.0	08 July 2010
Covering Letter	1	08 July 2010
Covering Letter		28 September 2010
Letter from Sponsor	1	22 June 2010
Questionnaire: Focus group Questions	1	06 July 2010
Letter of invitation to participant	1	07 July 2010
Participant Information Sheet: Staff Focus Group	1	05 July 2010
Participant Information Sheet: Service User Focus Group	2	24 September 2010
Response to Request for Further Information		28 September 2010
Participant Information Sheet: Service User Focus Group	1	07 July 2010
Participant Information Sheet: Staff Focus Group	2	24 September 2010
Participant Consent Form: Service User Focus Group	1	07 July 2010
Participant Consent Form: Staff	1	07 July 2010
Questionnaire: Focus Group Topic Guide	1	06 July 2010
Email correspondence Prof Craig & Ms Birken		27 September 2010
Evidence of insurance or indemnity	1	22 March 2010
Referees or other scientific critique report	1	15 January 2010

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email [referencegroup@nres.npsa.nhs.uk](mailto:referencegroup@nres.npsa.nhs.uk).

**Please quote this number on all correspondence: 10/H0807/69**

Yours sincerely

  
Prof. Tom Craig  
Vice Chair

Email: [audrey.adams@nhs.net](mailto:audrey.adams@nhs.net)

Enclosures: "After ethical review – guidance for researchers"

Copy to: Jenny Liebscher  
*R&D office for NHS care organisation at lead site*

## Appendix 2

**Institute of  
Psychiatry**

**at The Maudsley**

**Health Service & Population  
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Section for Recovery

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South London and Maudsley   
NHS Foundation Trust

### Participant Information sheet

#### Staff Focus Group

#### Study title

**Improving the ability to carry out everyday activities following  
discharge from hospital**

**Researcher: Mary Birken, PhD Student**

**Supervisors: Dr. Mike Slade and Dr. Claire Henderson**

**This study is being carried out as part of PhD student study.**

#### What is this study about?

The aim of this study is to explore what difficulties people experience with carrying out everyday activities after they have been discharged from an acute mental health ward. It also aims to explore what interventions staff use in practice currently to address these issues.

The results of this study will be used in the development of an intervention to improve a person's ability to carry out everyday activities. The interventions will take place following discharge from hospital. The aim of this type of intervention would be to prevent long term disability.

We would like to invite you to take part in this study. This information sheet tells you about the study. It will also explain what taking part in the study involves. It is important that you read the information sheet carefully and speak to the researcher before you decide to take part in the study.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South East London Research Ethics Committee. REC Reference number 10/H807/69.

## **Why have I been invited to take part in the study?**

You have been asked to take part in this study as you currently work in the community with people with a psychotic condition. You have also been invited to participate as you currently deliver interventions to address difficulties with every day activities.

## **What does taking part in the study involve?**

The study aims to explore the experiences of participants regarding carrying out interventions to address everyday activities following discharge from hospital.

The study will involve 6-8 people taking part in a focus group. The researcher leading the focus group will ask three or four questions to explore the participants' experiences of carrying out daily activities following discharge from hospital. The focus group will take place in a quiet room without interruptions to provide privacy for those participating. The focus groups will be recorded but no information that may identify you personally will be recorded. This provides us with valuable information to make sure we can develop an intervention to address the areas of importance to people following discharge from the acute wards.

## **What would I be expected to do?**

The focus group will be one hour long and will take place at a community mental health centre. The questions will be focused on your experience of carrying out interventions to address problems with daily activities following discharge from hospital. Refreshments will be provided.

## **Do I have to take part in the study?**

It is up to you whether or not you take part in the study. If you decide to take part you will be asked to sign a consent form and keep this information sheet to refer to. You are free to withdraw at any time from the study and without giving reason. A decision not to take part or to withdraw at any stage will not affect your employment.

## **What are the benefits of taking part?**

Taking part in this study means that you have the opportunity to contribute to the development of an intervention by sharing your experience with the researchers.

## **Will my taking part in the study be kept confidential?**

All information collected during this study will be kept strictly confidential. The exception to this is that as a researcher I have a legal duty of care to report any concerns regarding professional practice due to the vulnerable adults that provide a clinical service to. You will be asked to give only your first name during the study. The focus groups will be recorded on audio recorder. You will be asked to give only your first name during the focus groups to protect your identity. The audio recording will not contain any personal identifiable information, only your first name will be recorded. The audio recording will be transcribed and participants' names changed to pseudonyms to further protect your identity on the transcribed document.

Digital and computer sound files will be destroyed as soon as interviews have been transcribed. The transcripts will be stored on the academic institution's computer as a passworded document and will be accessible by the researcher and supervisors only.

If the researcher would like to use a direct quote from you in a publication or thesis, the researcher will contact you to ask your permission to use the quote.

## **What happens next?**

The researcher will arrange a time to offer to meet with you to discuss the study. You will have the opportunity to ask questions and be invited to sign a consent form.

**If you would more information about the study please contact:**

**Mary Birken: 020 78480503**

**Thank you for taking the time to read this study information sheet.**



## Appendix 3

**Institute of  
Psychiatry**

**at The Maudsley**

**Health Service & Population  
Research Department**  
Section for Recovery

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**South London and Maudsley**   
NHS Foundation Trust

### Focus Group Consent Form

#### Staff

#### Study Title

#### Improving the ability to carry out everyday activities following discharge from hospital

Participant's Statement:

I confirm that I have read and understand the information Sheet for the above study and I have had the opportunity to ask questions.

I understand that my participation is voluntary and that I am free to withdraw at anytime, without giving reason, without my employment or legal rights being affected.

I agree to take part in the above study.

-----

Name of participant

-----

Date

-----

Signature

Researcher's statement:

I confirm that I have carefully explained the nature of the study and explained what is required of the participant.

-----

Name of researcher

-----

Date

-----

Signature

## Appendix 4

### Topic Guide for Staff Focus Group

#### Setting the scene

It has been recognised that being in hospital and becoming unwell, can have an impact on a person's ability to carry out daily activities. It can disrupt people's daily lives.

We are interested in hearing your experience of enabling people with a diagnosed psychotic disorder getting back to daily activities after leaving hospital.

#### Question one

From discharge date to first month post discharge

A. From your experience of working with people with a diagnosed psychotic disorder following discharge from hospital what are the difficulties that you have observed they have had regarding their ability to carry out daily activities?

Prompt questions:

Any particular areas of daily activities where more difficulties observed?

Were the daily activities ones the person did prior to admission or new?

B. What daily activities have service users told you are important to them following during this first month?

#### Question Two

From two months to three months post discharge:

A. From your experience of working with people with a diagnosed psychotic disorder following discharge from hospital what are the difficulties that you have observed they have had regarding their ability to carry out daily activities?

B. What daily activities have service users told you are important to them following during this time?

#### Question three

Referring to this timescale again:

Can you describe some the ways in which you have supported people to improve their ability to carry out daily activities following discharge from hospital?

Prompt questions:

Do they use any specific named interventions?

## Appendix 5

**Institute of  
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**KING'S**  
*College*  
**LONDON**

South London and Maudsley   
NHS Foundation Trust

### **Participant Information sheet** **Service Users Focus Group**

#### **Study Title**

**Improving the ability to carry out everyday activities following  
discharge from hospital**

**Researcher: Mary Birken, PhD Student**

**Supervisors: Dr. Mike Slade and Dr. Claire Henderson**

#### **What is this study about?**

**This study is being carried out as part of PhD student study.**

The aim of this study is to explore what difficulties people experience with carrying out everyday activities after they have been discharged from an acute mental health ward.

The results of this study will be used in the development of an intervention to improve a person's ability to carry out everyday activities. The interventions will take place following discharge from hospital. The aim of this type of intervention would be to prevent long term disability.

We would like to invite you to take part in this study. This information sheet tells you about the study. It will also explain what taking part in the study involves. It is important that you read the information sheet carefully and speak to the researcher before you decide to take part in the study.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by South East London Research Ethics Committee.

REC Reference number: 10/H0807/69

## **Why have I been invited to take part in the study?**

You have been asked to take part in this study as you have been discharged from an acute mental health ward in the last 6 months and you are currently receiving care from the Support and Recovery team.

## **What does taking part in the study involve?**

The study aims to explore the experiences of participants regarding carrying out everyday activities following discharge from hospital.

The study will involve 4-6 people taking part in a focus group. All the participants will have left hospital in the last 6 months. The researcher leading the focus group will ask three or four questions to explore the participants' experiences of carrying out daily activities following discharge from hospital. The focus group will take place in quiet room that will provide privacy for those participating. The focus groups will be recorded but no information that may identify you personally will be recorded.

This provides us with valuable information to make sure we can develop an intervention to address the areas of importance to people following discharge from the acute wards.

## **What would I be expected to do?**

The focus group will be one hour long and will take place at your local community mental health centre. The questions will be focused on your experience of carrying out daily activities following discharge from hospital. Refreshments will be provided. You will be compensated for volunteering your time to take part in the study, by receiving a multi shop voucher for £20.

## **Do I have to take part in the study?**

It is up to you whether or not you take part in the study. If you decide to take part you will be asked to sign a consent form and keep this information sheet to refer to. You are free to withdraw at any time from the study and without giving reason. A decision not to take part or to withdraw at any stage will not affect the standard of care you receive.

## **What are the benefits of taking part?**

Taking part in this study means that you have the opportunity to contribute to the development of an intervention by sharing your experience with the researchers.

## **Will my taking part in the study be kept confidential?**

All information collected during this study will be kept strictly confidential. The focus groups will be recorded on audio recorder. You will be asked to give only your first name during the focus groups to protect your identity. The audio recording will not contain any personal identifiable information, only your first name will be recorded. The audio recording will be transcribed and participants' names changed to pseudonyms to further protect your identity on the transcribed document.

Digital and computer sound files will be destroyed as soon as interviews have been transcribed. The transcripts will be stored on the academic institution's computer as a passworded document and will be accessible by the researcher and supervisors only.

If the researcher would like to use a direct quote from you in a publication or thesis, the researcher will contact you to ask your permission to use the quote.

## **What happens next?**

If you would like to participate in this study and/or you would like to further discuss this study, you will be invited to arrange a time to meet with the researcher who will discuss the purpose of the study with you. You can ask the researcher any questions you have and you will be invited to complete a consent form. The focus group will take place within a week after your meeting with researcher.

**For more information about the study please contact:**

**Mary Birken 020 78480852**

**Thank you for taking the time to read this study information  
sheet.**

## Appendix 6

**Institute of  
Psychiatry**

**at The Maudsley**

**Health Service & Population  
Research Department**  
Section for Recovery

Box PO29  
De Crespigny Park  
Denmark Hill  
London SE5 8AF  
Tel +44 (0)20 7848 0703  
Fax +44 (0)20 7277 1462



South London and Maudsley   
NHS Foundation Trust

### Consent Form

#### Service User Focus Group

##### Study Title

**Improving the ability to carry out everyday activities following  
discharge from hospital**

##### Participant's Statement:

1. I confirm that I have read and understand the information Sheet for the above study and I have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at anytime, without giving reason, without my healthcare or legal rights being affected.
3. I agree to take part in the above study.

-----

Name

-----

Date

-----

Signature

##### Researcher's statement:

I confirm that I have carefully explained the nature of the study and explained what is required of the participant.

-----

Name

-----

Date

-----

Signature

## **Appendix 7**

### **Topic Guide Service User Focus Group**

#### **Setting the scene**

We are interested in hearing about your experience of getting back to daily activities after leaving hospital. Examples of everyday activities are, looking after yourself and your home, activities outside the home like shopping, meeting friends, sports, volunteering or attending a course.

#### **Question One**

To start off, Can you all tell us what daily activities you spent your time doing, during the first month after you came out of hospital?

And also any daily activities you wanted to do during this time but were unable?

*Prompt questions:*

How did you manage looking after yourself and your home?

What kind of things did you do/ or wanted to do outside your home?

#### **Question Two**

Looking at two and three months after leaving hospital:

Can you all tell us what daily activities you spent your time doing, during the second and third month after you came out of hospital?

And also any daily activities you wanted to do during this time but were unable?

#### **Question Three**

What activities were important for you to be able to do better, or more independently, during these first three months?

*Prompt question:*

Activities outside the house

Looking back over the last three to six months since you left hospital- what do you feel are the most important daily activities that you would like to carry out after leaving hospital?

Prompt: What about activities outside the house?

## Appendix 8

### Systematic Review Data Extraction Form

Reference details

Reference ID

First Author

Year

Journal

Title

Setting

Country

#### Interventions

##### Experimental Title

Description

Theoretical base

Level of standardisation

Fidelity assessment

##### Comparison Title

Description

Diagnosis: Schizophrenia

Schizoaffective disorder

Other

Study Design

Design

Study Questions

Experimental:

RCT

Quasi- experimental

Observational:

Cohort

Cross-Sectional

Controlled before and after

Uncontrolled before and after

Case Series

Other, describe:

Effectiveness

Efficacy

Other, describe:

Evaluation

Primary outcome measure:

Additional outcome measures:



## **Appendix 9**

### **GLOW Manual**

#### **Graduating Living skills Outside the Ward**

## **Summary**

This is the intervention manual for GLOW - Graduating Living skills Outside the Ward. It is written for Occupational Therapists working in community settings with people with a diagnosed psychotic disorder, following discharge from hospital.

GLOW is a stepped intensity intervention based on The Model of Human Occupation (Kielhofner, 2008) and the Intentional Relationship Model (Taylor, 2008), and has a number of components:

1. Assessment of volition, habituation and performance capacity
2. Developing self management of occupational performance
3. Activity Grading
4. Environmental Enhancements & considerations

The intervention is 4 months in duration consisting of:

Four weeks- high intensity

Six weeks -medium intensity

Six weeks -low intensity

## **Summary of evidence**

Service users, staff and theory describe a gradual process of picking up self-care, domestic chores and leisure following discharge from an acute ward, which is seen as a sheltered environment where many self-care tasks are done or with staff providing prompting to do tasks. The environment provides limited opportunity to participate in leisure activities. The literature, service users and staff also report that in the first month, things are slow, with time needed to process what happened and to fully recover from symptoms- therefore active support is needed using a graded approach, to ensure basic needs are met and without creating dependency. Service users described the importance of having a purpose to “make you leave the house”, such as a regular sport/ leisure pursuit.

## **Model of Human Occupation**

The intervention is based on The Model of Human Occupation, as this model of practice was assessed as being most suitable for use in community mental health. Additionally, it is evidence based, in that the constructs have been tested for validity within the model.

MOHO seeks to explain how occupation is motivated, patterned, and performed. By offering explanations of such diverse phenomena, MOHO offers a broad and integrative view of human occupation. Within MOHO, humans are conceptualized as being made up of three interrelated components: volition, habituation, and performance capacity. Volition refers to the motivation for occupation, habituation refers to the process by which occupation is organized into patterns or routines, and performance capacity refers to the physical and mental abilities that underlie

skilled occupational performance. MOHO also emphasizes that to understand human occupation, we must understand the physical and social environments in which it takes place. Therefore, this model aims to understand occupation and problems of occupation that occur in terms of its primary concepts of volition, habituation, performance capacity, and environmental context. It is based on the open system and provides a systematic way of analyzing the interaction of the system (i.e., a human) with the environment.

The open system in MOHO interacts with the environment via four mechanisms:

1. Intake: This is the reception of information from the environment. It contains a negative/positive filter.
2. Throughput: This takes the information received by the individual through the internal systems outlined above.
3. Output: The individual's behaviour which is based on his/her judgment of the summarized information resulting from throughput.
4. Feedback: Here one is informed about the consequences of his/her action.

### **The Intentional Relationship Model**

This model is used to outline the therapeutic skills used by the Occupational Therapist in the three levels of intensity of the intervention. The model conceptualizes the processes involved in therapeutic use of self. It is intended to complement existing occupational therapy conceptual practice framework. The model outlines six therapeutic modes which the OT uses in practice when engaging with service users. A therapeutic mode is a specific way of relating to a service user. The six modes are used interchangeably depending on the service users needs. These therapeutic modes are incorporated into this intervention manual to describe the therapeutic approach used in each of the three levels of intensity.

### **Components of the intervention**

Component 1: Assessment of volition, habituation and performance capacity

Assessment begins the therapeutic process between the clinician and service user, and intervention can take place during assessments as the discussion can involve solutions to problems identified during intervention.

The following assessments will be carried out during first two weeks of intervention in conjunction with the service user. The first two weeks of the intervention may take place whilst the service user is still an inpatient and will include a home visit.

### **Assessment tools**

MOHOST: Model of Human Occupation Screening tool (Parkinson, et al, 2006)

This is an observational assessment that addresses the majority of MOHO concepts (volition, habituation, skills, and environment), allowing the therapist to gain an overview of the client's occupational functioning.

REIS (short form) - non-standardised semi structured assessment tool.

(Parkinson et al, 2011)

This is a non-standardised semi-structured assessment tool. The short form version provides a structure for gathering and summarizing data about the home environment, and generating recommendations to enhance the qualities of the environment. A person's home environment is an important factor in developing routines. Within the home, habit can be viewed as the tendencies to perform in consistent ways as a response to the environment.

Interest checklist:

The UK Modified Interest Checklist gathers information on a client's strength of interest and engagement in 74 activities in the past, present, and future. Interests are listed in nine categories that focus on different types of activity choices.

### **Component 2 Developing self management of occupational performance**

Providing information and explaining occupation in relation to mental health. Occupational Therapists hold knowledge and skills regarding occupation and occupational performance that can be imparted to service users to enable them to use this knowledge in their own lives beyond OT intervention. The aim of this component is to support self-management and self direction, in line with personal recovery principles.

### **Component 3 Activity grading**

Sequentially increasing the demands of an activity on a person to stimulate improvement in their functional ability. This also enables the person to experience success, which increases their motivation for occupation. Knowledge of task and skills required are developed through this process also, this is done by the OT communicating all aspects of the occupation, with the service user.

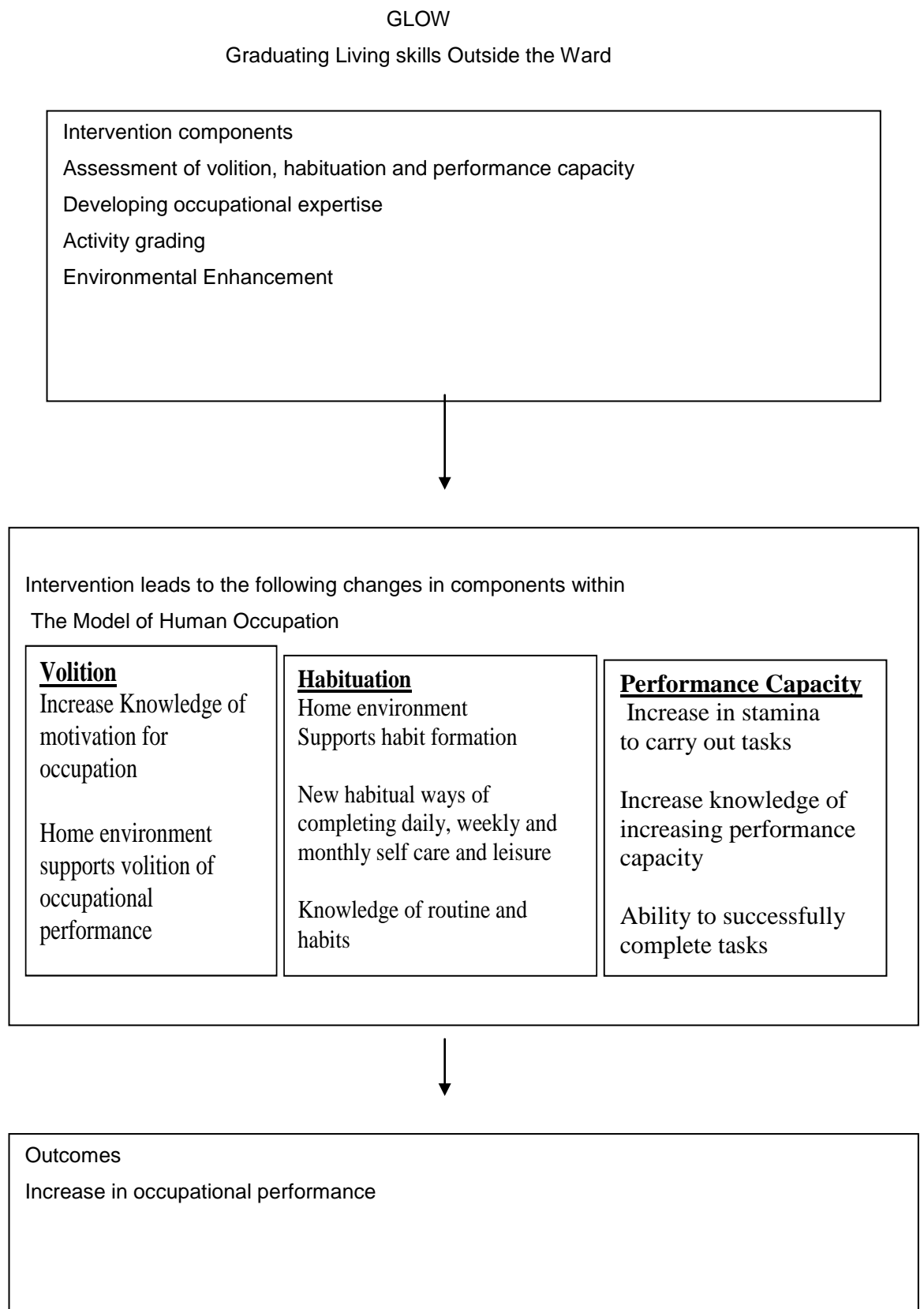
For example, home and self-care knowledge and skills will be discussed during activity grading regarding the following occupations, personal hygiene, clothes care, food care, cooking

methods, budgeting. Written information will be provided regarding cooking methods, budgeting, clothes care and personal hygiene as required.

#### Component 4 Environmental Enhancements & considerations

Adjusting the physical environment and creating the optimum environment to enable the person to engage in self-care and leisure occupations. This can take place in the persons home, for example by placing items of interest to increase motivation for occupation, or placing environmental supports to promote routine. Environmental enhancement can take place in the community also, for example, identifying support mechanisms and best environment to facilitate food shopping or leisure.

Figure 1: Model of the Intervention



## **The Intervention**

### **Identification of goals**

Following discussion of strengths and areas for development identified during assessment regarding self-care and leisure and past routine, goals are agreed in these areas. During the high intensity intervention stage, short term weekly goals are agreed regarding meeting basic self-care needs and re-establishing or establishing a daily/ weekly routine. Goals regarding leisure occupations are agreed when service users identifies need to prioritize these.

### **High Intensity four weeks**

Occupational Therapist to visit twice weekly (or visit and telephone call per week)

Therapeutic mode: Instructing, encouraging advocating

#### **Activity grading**

Day by day goal setting regarding increasing stamina through adding occupations to the daily routine.

Occupational Therapist to carry out tasks alongside Service user to provide initiation of tasks to meet basic needs regarding self-care, as prioritised by service users.

Demonstrate and verbalise stages of task through discussion with service user.

For example, re-organizing, tidying and cleaning flat, shopping for food, or paying bills. OT provides written information regarding tasks, for example, use of washing machine, cooking methods.

#### **Enabling Service users to become experts in their own occupation**

Developing an understanding of occupation and its role in health, apply information to home environment. Explain and provide written information regarding purpose of establishing a routine.

By the end of six weeks, service user can identify own barriers to occupations and problem solve their options and alternatives

#### **Environmental Enhancements to support occupational performance:**

Discussion regarding REIS home environment findings and methods to enhance environment to promote routine and engagement in occupational performance.

Methods to enhance the home environment:

- To promote the development of a routine

- Introduction of a calendar, diary, clock, shopping list and "to do" memo pads and an alarm clock.

-To support daily tasks

Establish files for bills, fix location for contact details for services, appointment cards as well as ensuring the necessary equipment is available to carry out self-care, cooking and home care tasks.

-To promote leisure interests

Identify and place meaningful interests into home environment, for example, music, magazines, books, DVDs.

Immediate locality environment: discussion of completed analysis of environmental impact regarding accessing community for basic food items.

Methods to compensate for negative environmental impact: Identify preferred shop for buying groceries which offers least environmental barriers. Identify preferred venue for leisure occupations. Identifying best route to shops and local leisure resources.

### **Medium Intensity Six weeks**

Occupational Therapist to visit twice weekly during this six weeks, and to meet in community increasingly during final three weeks of medium intensity intervention. Interventions focus increasingly on leisure occupations, as identified by service users.

Therapeutic mode: problem solving, collaborating, encouraging.

Enabling Service users to become experts in their own occupation

Service user identifies own barriers to occupations and problem solve their options and alternatives

By the end of six weeks service users redesign their own occupations by adjusting their daily routine.

Environmental Enhancements to support occupational performance

Review methods used to enhance home environment, further enhance if service users identifies the need.

Immediate locality environment: Further environmental analysis of barriers to accessing community for leisure and social contact. Identification of methods to support access, for example, best environment to meet friends or family, access local information.

Activity Grading

Increasing emphasis on occupational performance in community, for example, using transport, leisure resources.

Service user takes increasing responsibility for completing tasks throughout six weeks with OT present for first two weeks to provide prompting, further assess, and suggest support mechanisms where required for Service user to complete the task.



### **Low intensity Four weeks**

Occupational Therapist to meet service user in community weekly, with phone calls in between as required. Home visit on final session to review achievements.

Therapeutic mode: collaborative, problem solving and encouraging.

Activity grading

Service users independently carries out occupations with supports in place as required. Review community supports and revise if needed.

Enabling Service users to become experts in their own occupation

Service users redesign their own occupations by adjusting their daily routine and planning future occupational goals.

Environmental Enhancement:

Review environmental enhancements in place, revise if need identified by service user.

---

Definitions:

Occupational performance:

“Choosing, organizing and carrying out an occupation in interaction with the environment”  
(Creek, 2010)

It results from heterarchical contribution from the components of the person, namely: volition, habituation and performance capacity and the environment. Occupational performance is dynamic in nature, because it is influenced and shaped by external environment that is continuously changing. It is also spontaneous and must be understood within the context of emerging action and conditions (Kielhofner, 2008)

Intentional relationship model- therapeutic modes:

Instructing

Carefully structuring therapy activities and being explicit with clients about the plan, sequence, and events of therapy. Providing clear instruction and feedback about performance.

Encouraging

Seizing the opportunity to instil hope in a client. Celebrating a client's thinking or behaviour through positive reinforcement. Conveying an attitude of joyfulness, playfulness, and confidence.

### Advocating

Ensuring that the client's rights are enforced and resources are secured. May require the therapist to serve as mediator, facilitator, negotiator, enforcer, or other type of advocate with external persons and agencies.

### Problem-solving

Facilitating pragmatic thinking and solving dilemmas by outlining choices, posing strategic questions, and providing opportunities for comparative or analytical thinking.

### Collaborating

Expecting the client to be an active and equal participant in therapy. Ensuring choice, freedom and autonomy to the greatest extent possible.

### Activity grading

Sequentially increasing the demands of an activity on a person to stimulate improvement in their functional ability (Crepeau 2003).

Activity grading is on a continuum:

OT initiates a task – the service user initiates a task

OT suggests a task- the service user identifies priority task

OT provides instructions and prompts to carry out task- service users directs task

Brief length of time doing task- prolonged engagement in task.

### Environment

The concept of the environment has been defined within the Model of Human Occupation as

The physical and social, cultural, economic, and political features of one's contexts that impact upon the motivation, organization, and performance of occupation. It includes the following dimensions: objects that people use when doing things, the spaces within which people do things, the occupational tasks that are available, expected, and or required by the context, social groups (family, friends, co-worker, neighbours) encountered, the culture that infuses and influences both physical and social aspects of the environment and the political and economic context that influences such things as freedoms and resources relevant to occupation. (Kielhofner 2008)

### Environmental Enhancement and considerations:

The negative impact of the environment on occupational performance can be reduced by introducing objects into the environment, for example tools, or meaningful items. Another approach to reducing negative impact of the environment on occupational performance is to

identify most suitable environment to carry out occupations, for example, identifying most supporting shopping environment, or leisure environment, local to the individual.

Developing expertise in their own occupation:

Occupational Therapists hold knowledge and skills regarding occupation and occupational performance that can be imparted to service users to enable them to use this knowledge in their own lives beyond OT intervention.

## References

Creek, J. (2010). *The Core Concepts of Occupational Therapy*, London: Jessica Kingsley

Crepau, E.R., (2003). Analyzing occupation and activity: A way of thinking about occupational performance in *Willard & Spackman's Occupational Therapy*. 10<sup>th</sup> Edition. Philadelphia, Lippincott Williams and Wilkins

Kielhofner, G. (2008) *Model of Human Occupation*. Philadelphia, Lippincott Williams and Wilkins.

Parkinson, S., Fisher, G., Fisher, J. (2011) *THE RESIDENTIAL ENVIRONMENT IMPACT SURVEY – SHORT FORM (REIS-SF) (UK Version 2.2)*. Chicago, The Model of Human Occupation Clearinghouse, Department of Occupational Therapy, University of Illinois at Chicago.

Parkinson, S., Forsyth, K. & Kielhofner, G. (2006) *The Model of Human Occupation Screening Tool (MOHOST) Manual, Version 2*. Chicago, The Model of Human Occupation Clearinghouse, Department of Occupational Therapy, University of Illinois at Chicago.

Taylor, R.R. (2008) *The Intentional Relationship- Occupational Therapy and use of self*. Philadelphia, F.A.Davis Company.

## **Appendix 10**

### **GLOW Training Schedule for OTs**

#### **Introduction**

Present summary of SU and staff Focus Groups, highlighting needs to be addressed for intervention

Presentation and discussion of findings from literature review regarding OP.

Presentation and brief discussion regarding MOHO and experience of use in clinical practice

Presentation and discussion regarding therapeutic use of self and Intentional relationship model

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Overview of GLOW Intervention procedure

Baseline measures

Re-administer measures at end of intervention

Components of GLOW

Assessment tools:

Present practice examples and discuss tools:

Mohost

REIS-SF

Interest checklist

- Developing self management of OP
- Activity Grading
- Environmental Enhancements and considerations:

Adjusting the physical environment: home environment

Creating optimum environment to enable self care and leisure.

## Appendix 11

### NRES Committee London - East

REC Offices  
Room 10  
4th Floor West  
Charing Cross Hospital  
Fulham Palace Road  
London  
W6 8RF  
Telephone: 020 331 10100

16 August 2011  
Miss M Birken  
PhD student  
Institute of Psychiatry, at Kings College, London  
Box PO29,  
De Crespigny Park,  
Denmark Hill, London  
SE5 8AZ

Dear Miss Birken

**Study title: An investigation of the effectiveness of an intervention to improve the occupational performance of people with a diagnosed psychotic disorder, following discharge from an acute inpatient mental health ward.**

**REC reference: 11/LO/1061**

**Protocol number: N/A**

Thank you for your letter of 28 July 2011, responding to the Committee's request for further

information on the above research and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC.

A list of the sub-committee members is attached.

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the

above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

#### **Ethical review of research sites**

##### **NHS sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of

the study (see "Conditions of the favourable opinion" below).

##### **Non-NHS sites**

The Committee has not yet been notified of the outcome of any site-specific assessment

(SSA) for the non-NHS research site(s) taking part in this study. The favourable opinion does not therefore apply to any non-NHS site at present. We will write to you again as soon

as one Research Ethics Committee has notified the outcome of a SSA. In the meantime no

study procedures should be initiated at non-NHS sites.

#### ***Conditions of the favourable opinion***

*The favourable opinion is subject to the following conditions being met prior to the start of the study.*

*Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.*

*Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.*

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.*

*For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.*

*Sponsors are not required to notify the Committee of approvals from host organisations*

**It is the responsibility of the sponsor to ensure that all the conditions are complied**

**with before the start of the study or its initiation at a particular site (as applicable).**

#### **Approved documents**

The final list of documents reviewed and approved by the Committee is as follows:

##### *Document Version Date*

Covering Letter 17 June 2011

Evidence of insurance or indemnity 10 June 2011

Investigator CV 17 June 2011

Other: letter from funder 22 June 2010

Other: GLOW Intervention Manual 10 June 2011

Other: summary cv for student 17 June 2011

Other: summary cv for supervisor 10 June 2011

Other: Independent Living Skills Survey 1 25 July 2011

Participant Consent Form: For Staff 2 26 July 2011

Participant Consent Form: For Service User 2 26 July 2011

Participant Information Sheet: For Staff 2 26 July 2011

Participant Information Sheet: For Service User 2 26 July 2011

Protocol 1 10 June 2011

Questionnaire

Questionnaire 1 10 June 2011

Questionnaire 1 10 June 2011

Questionnaire 1 10 June 2011

REC application 1 17 June 2011

Referees or other scientific critique report 15 January 2010

Response to Request for Further Information 28 July 2011

#### **Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating

Procedures for Research Ethics Committees in the UK.

#### **After ethical review**

Reporting requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National

Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

**11/LO/1061 Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project

Yours sincerely

**Revd Dr Joyce Smith**

**Chair**

Email: [laura.keegan@nhs.net](mailto:laura.keegan@nhs.net)

*Enclosures: List of names and professions of members who were present at the meeting*

"After ethical review – guidance for researchers"

*Copy to: Ms Jennifer Liebscher, Institute of Psychiatry, King's College London*

**NRES Committee London - East**

**Attendance at Sub-Committee of the REC**

**Committee Members:**

*Name Profession Present Notes*

Revd Dr Joyce Smith Chair - Clergy/Consultant

Dentist

Yes

Dr Elizabeth Webster General Practitioner Yes

## Appendix 12

**Institute of  
Psychiatry**

**at The Maudsley**

**Health Service & Population  
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Section for Recovery

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Fax +44 (0)20 7277 1462

**KING'S**  
*College*  
**LONDON**

### Staff Participant Information Sheet

#### Study title

#### **Improving the ability to carry out everyday activities following discharge from hospital**

**Researcher: Mary Birken, PhD Student**

**Supervisors: Dr. Mike Slade and Dr. Claire Henderson**

We would like to invite you to take part in a research study. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. This information sheet tells you about the study. It will also explain what taking part in the study involves. It is important that you read the information sheet carefully before you decide to take part in the study. Please take time to read the following information carefully and discuss it with others if you wish.

#### **What is the purpose of this study?**

**This study is being carried out as part of PhD student study.**

This research study is looking at how to improve service users' ability to carry out everyday activities after leaving hospital. We are training some Occupational Therapy staff in community mental health services to provide an intervention to improve service users' ability to carry out everyday activities following discharge from hospital, in addition to their usual treatment. The intervention- GLOW- Graduating living skills outside the ward, is a manualised intervention developed during the first stage of this study. The intervention has been developed using best available evidence and is based on OT theory and models.

The Occupational Therapy staff who have received the training will work with service users with a diagnosed psychotic condition so they can meet their basic needs, for example, to eat and



look after themselves and their accommodation after you leave hospital. The intervention will focus on what self care and leisure are most important to the service user.

The interventions will take place following discharge from hospital. The aim of this type of intervention would be to prevent long term disability

We would like to invite you to take part in this study. This information sheet tells you about the study. It will also explain what taking part in the study involves. It is important that you read the information sheet carefully and speak to the researcher before you decide to take part in the study.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NRES Committee London-East. REC Reference: 11/LO/1061

## **Why have I been invited to take part in the study?**

You have been asked to take part in this study as you currently work in the community with people with a psychotic condition.

## **What does taking part in the study involve?**

If you decide to take part in the study, you will be asked to attend a half day training session regarding using the GLOW intervention manual, you will be expected to carry out the GLOW intervention with service users meeting the inclusion criteria and who live within your team catchment area. You will be expected to see the service users allocated to you for four months duration on a one to one basis. The intervention comprises of assessment of volition, habituation and performance capacity, developing self management of occupational performance, activity grading, and environmental enhancements and considerations. You will be expected to carry out twice weekly home visits for first four weeks, weekly visits/ meetings with service users at home or in community for following six weeks. During the final six weeks of weekly contact with service user, this could be meeting them in the community, phone call or final visit at their home.

You will receive regular phone or face to face supervision from the researcher regarding use of the intervention.

The service users' care co-ordinators will also be working with the service user during this time to carry out the normal treatment the service user would expect from them following discharge from hospital.

You will also be asked to complete a questionnaire and semi structured interview on completion of carrying out the intervention for four months, regarding your experience of using the intervention. The interview will be recorded but you will be asked to use your first name only during the interview to protect your identity.

## **Do I have to take part in the study?**

It is up to you whether or not you take part in the study. If you decide to take part you will be asked to sign a consent form and keep this information sheet to refer to. You are free to withdraw at any time from the study and without giving reason. A decision not to take part or to withdraw at any stage will not affect your employment.

## **What are the possible benefits of taking part?**

You will have the opportunity to participate in training regarding an evidence based intervention and gain experience in using a manualised intervention tool that is evidence based.

## **Will my taking part in the study be kept confidential?**

All information collected during this study will be kept strictly confidential. The exception to this is that as a researcher I have a legal duty of care to report any concerns regarding professional practice due to the vulnerable adults that you provide a clinical service to. You will be asked to give only your first name during the study. The interview will be recorded on audio recorder. You will be asked to give only your first name during the interview to protect your identity. The audio recording will not contain any personal identifiable information, only your first name will be recorded. The audio recording will be transcribed and participants' names changed to pseudonyms to further protect your identity on the transcribed document.

Digital and computer sound files will be destroyed as soon as interviews have been transcribed. The transcripts will be stored on the academic institution's computer as a passworded document and will be accessible by the researcher and supervisors only.

If the researcher would like to use a direct quote from you in a publication or thesis, the researcher will contact you to ask your permission to use the quote.

## **What happens next?**

The researcher will arrange a time to offer to meet with you to discuss the study. You will have the opportunity to ask questions and be invited to sign a consent form.

## **What will happen to the results of the study?**

The results of this study will be published in scientific journals, conferences and reports to NHS service managers. The results of this study will also be presented to staff and service users within South London & Maudsley NHS Foundation Trust.

## **What if there is a problem?**

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer the questions. Their contact details are given below. If you remain unhappy and wish to complain formally, you can do this through the Complaints Procedure of the Institute of Psychiatry, Kings College London via the Dean's Office, Institute of Psychiatry, De Crespigny Park, London SE5 8AF.

If you would more information about the study please contact:

Mary Birken: 020 78480513

Thank you for taking the time to read this study information sheet.

## Appendix 13

**Institute of  
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at The Maudsley

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**KING'S**  
*College*  
**LONDON**

### Staff Consent Form

#### Study Title

**Improving the ability to carry out everyday activities following discharge  
from hospital**

**Participant's Statement:**

**Please initial box**

1. I confirm that I have read and understand the Staff Participant Information Sheet dated: 26/07/2011(version 2) for the above study. I have had the opportunity to ask questions and have them had these answered satisfactorily
2. I understand that my participation is voluntary and that I am free to withdraw at anytime, without giving reason, without my employment or legal rights being affected.
3. I understand the researcher has a legal duty of care to report any concerns regarding professional practice due to the vulnerable adults that you provide a clinical service to.
4. I understand that the interview will be audio recorded and that the contents of tape will be kept confidential.
5. I give my permission to use quotes and I understand that these will be anonymised.
6. I agree to take part in the above study.

☐☐☐☐☐☐

-----  
Name of participant

-----  
Date

-----  
Signature

-----  
Name of researcher

-----  
Date

-----  
Signature

## Appendix 14

**Institute of  
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at The Maudsley

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**LONDON**

## Service user Participant Information sheet

### Study Title

### **Improving the ability to carry out everyday activities following discharge from hospital**

**Researcher: Mary Birken, PhD Student**

**Supervisors: Dr. Mike Slade and Dr. Claire Henderson**

We would like to invite you to take part in a research study. Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. This information sheet tells you about the study. It will also explain what taking part in the study involves. It is important that you read the information sheet carefully and speak to the researcher before you decide to take part in the study. Please take time to read the following information carefully and discuss it with others if you wish. Please take time to decide whether or not you wish to take part.

### **What is the purpose of this study?**

**This study is being carried out as part of a PhD student study.**

This research study is looking at how to improve service users' ability to carry out everyday activities after leaving hospital. We are training some staff in community mental health services to provide an intervention to try to improve service users' ability to carry out everyday activities following discharge from hospital, in addition to the usual treatment received following discharge.

The intervention is called GLOW- graduating living skills outside the ward. The staff who have received the training will work with you so you can meet your basic needs, for example, to eat

and look after yourself and your accommodation after leaving hospital. They will focus on what self care and leisure are most important to you. The aim of this type of intervention would be to prevent long term problems with carrying out self care and leisure.

The researcher will compare this to staff providing treatment you would usually receive from the community mental health team after leaving hospital.

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by NRES Committee London-East. REC Reference: 11/LO/1061

## **Why have I been invited to take part in the study?**

You have been asked to take part in this study as you have left, or are about to leave a mental health ward and you are currently receiving care from a community mental health team.

## **What will I have to do?**

If you decide to take part, when you leave hospital, you will either:

- have your care co-ordinator work with you, carrying out the usual treatment you would expect after leaving hospital.

### **OR**

- Have your care co-ordinator AND an Occupational Therapist will work with you for four months following discharge from hospital.

The researcher will inform you which intervention you will receive when you leave hospital.

**If you are in the group of patients that receive the intervention**, an Occupational Therapist will work with you for four months to support you to identify and prioritise self care and leisure activities to meet your basic needs after you have left the ward. Examples of this would be looking after yourself and your home initially on leaving hospital and supporting you to access shops and leisure resources in the community when you feel ready to do so. You will meet with the Occupational Therapist at your home, in your neighbourhood or elsewhere in the community.

They will meet with you:

- Twice weekly for first four weeks
- Weekly for a further six weeks
- Weekly phone call or meeting for final six weeks.

If you decide to take part, then you will be asked to answer some short questions about your ability to carry out every day activities, after you leave hospital. You will be asked to answer the same questions, four months later with an additional questionnaire, and finally seven months after you have left hospital. The questionnaires will take up to an hour to complete. The

additional questionnaire to be answered four months after leaving hospital will take up to twenty minutes to complete.

If you join the study, relevant sections of your medical notes and the data collected during the study may be looked at by individuals from Institute of Psychiatry, Kings College London, from regulatory authorities or from the NHS trust, where it is relevant to my taking part in this research. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

## **Do I have to take part in the study?**

It is up to you whether or not you take part in the study. If you decide to take part you will be asked to sign a consent form and keep this information sheet to refer to. You have the right to choose to not receive the intervention from the Occupational Therapists and you can continue to take part in the study receiving the treatment you would normally receive after you have left hospital. You are free to withdraw at any time from the study and without giving reason. A decision not to take part or to withdraw at any stage will not affect the standard of care you receive.

## **What are the possible benefits of taking part?**

In the longer term, the study aims to increase knowledge about how to successfully improve a person's ability to carry out everyday activities after they leave hospital.

Each service user participating in the study will receive a total of £10. to reimburse you for your time and effort involved in participating in the study.

## **Will my taking part in the study be kept confidential?**

All information collected during this study will be kept strictly confidential. Data collected will be anonymised by removing your name and other personal details.

If the researcher would like to use a direct quote from you in a publication or thesis, the researcher will contact you to ask your permission to use the quote. Your care co-ordinator will know that you are taking part in the study.

## **What happens next?**

If you would like to participate in this study and/or you would like to further discuss this study, you will be invited to arrange a time to meet with the researcher who will discuss the purpose of the study with you. You can ask the researcher any questions you have and you will be invited to complete a consent form.

## **What will happen to the results of the study?**

The results of this study will be published in scientific journals, conference and reports to NHS service managers. The results of the study will also be presented to staff and service users within South London & Maudsley NHS Foundation Trust.

## **What if there is a problem?**

**If you have a concern** about any aspect of this study, you should speak to the researchers who will do their best to answer the questions. Their contact details are given below. **If you remain unhappy and wish to complain formally, you can do this through the Complaints Procedure of the Institute of Psychiatry, Kings College London via the Dean's Office, Institute of Psychiatry, De Crespigny Park, London SE5 8AF.**

This study was given approval by the NRES Committee London-East, which is part of the NHS. As such, you may wish to raise your concerns about the study through the NHS. The Patient Advice and Liaison Service (PALS) can discuss any problem you may have with the study. You can access information about PALS online here:

<http://www.pals.nhs.uk/>

The nearest PALS office to this study is located at The Maudsley Hospital, and their contact details are given below:

Patient Advice & Liaison Service

The Maudsley Hospital,

Denmark Hill,

London SE5 8AZ

**Telephone:** 0800 731 2864 (freephone), **Email:** [pals@slam.nhs.uk](mailto:pals@slam.nhs.uk)

**For more information about the study please contact:**

**Mary Birken 020 78480513**

**Thank you for taking the time to read this study information sheet.**



## Appendix 15

**Institute of  
Psychiatry**

at The Maudsley

**Health Service & Population  
Research Department**  
Section for Recovery

Box PO29  
De Crespigny Park  
Denmark Hill  
London SE5 8AF  
Tel +44 (0)20 7848 0703  
Fax +44 (0)20 7277 1462

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### Service User Consent Form

#### Study Title

### Improving the ability to carry out everyday activities following discharge from hospital

**Participant's Statement:**

Please Initial Box

- 1 I confirm that I have read and understand the Service User Participant Information Sheet dated: 26/07/11 (version 2) for the above study. I have had the opportunity to ask questions and have had these answered satisfactorily.
- 2 I understand that my participation is voluntary and that I am free to withdraw at anytime, without giving reason, without my medical care or legal rights being affected.
- 3 I understand that half of the participants in the study will not receive the intervention and that I may be in the group that does not receive the intervention.
- 4 I agree to receive the intervention if I am in the group selected to receive it
- 5 I understand that relevant section of my medical notes and data collected during the study may be looked at by individuals from King's College London, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

6. I agree to take part in this study.

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Name of participant

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Name of researcher

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Date

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Date

-----

Signature

-----

Signature

**Appendix 16**  
**GLOW**  
**(Graduating Living skills Outside the Ward)**  
**Study**  
**Study recruitment screening process**

**Inclusion Criteria:**

- **Primary diagnosis of psychotic disorder:** ☐

Schizophrenia ☐

Schizo-affective ☐

**Excluded:**

Primary diagnosis/primary current presentation of Substance-Induced Psychotic Disorder

Primary diagnosis/primary current presentation of Psychosis with major substance misuse

- **Age 18-65** ☐
- **Identified problems with occupational performance in self care and/or leisure in community** ☐

For example, History of problems with looking after their homes, establishing a daily routine prior to admission, problems with OP in community, lack of community engagement identified through OT screening /assessment/discharge planning.

- **Discharge planned for next two weeks OR been discharged in last two weeks** ☐

Many thanks for help.

Any queries contact: [mary.birken@kcl.ac.uk](mailto:mary.birken@kcl.ac.uk)

020 7848 0513.

## Appendix 17

### Service User Participant Acceptability and Process Evaluation Questionnaire

GLOW study

Service User Participant Acceptability and Process Evaluation Questionnaire

Fidelity Questionnaire

Study ID: \_\_\_\_

Researcher will ask the following questions:

Fidelity to intervention manual questions-

In the last four months has the Occupational Therapist

Used the following assessments with you-

-MOHOST: about your skills and abilities	Yes	No
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-REIS: About your home	Yes	No
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-Interest Checklist	Yes	No
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-given you written information regarding daily living tasks, e.g., cooking, washing clothes	Yes	No
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-Given you written information regarding Occupation	Yes	No
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-Talked to you about your home environment	Yes	No
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Discussed items to have in your home to help you carry out day to day tasks?	Yes	No
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Review your progress and set future goals with you?	Yes	No
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Work with you in a way that gradually gave you more responsibility for tasks, while she became less involved in tasks?	Yes	No
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Acceptability Questionnaire

The intervention I received was satisfactory to me	Yes	No
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I would be willing to receive this intervention again, in the future	Yes	No
I would suggest this intervention to others	Yes	No
The intervention would not result in unhelpful or harmful effects	Yes	No
Overall, the intervention would be beneficial for people after leaving hospital	Yes	No
What components of the intervention do you think worked best?		
In what way do you think they were effective?		
What components of the intervention that you think were least effective?		
In what way do you think these components were least effective?		

## Appendix 18

### Staff Participant Acceptability & Process Evaluation Questionnaire

**Institute of  
Psychiatry**

**at The Maudsley**

**Health Service & Population  
Research Department**  
Section for Recovery

Box PO29  
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#### Staff Participant Acceptability & Process Evaluation Questionnaire

#### Fidelity Questionnaire

Study ID\_\_\_\_\_

In relation to your clinical role implementing this intervention have you carried out the following?

Complete MOHOST

Yes No Partially

If not, Why:

Complete REIS-SF

Yes No Partially

If not, Why:

Complete interest checklist

Yes No Partially

If not, Why:

high intensity four weeks completed

Yes No Partially

If not, Why:

A. Two visits per week

Yes No Partially

If not, why:

Therapeutic stance- instructing

Yes No Partially

If not, why:

For the three levels of intensity did you use following interventions as described for that level?

Developing self management of OP-Routine

Yes No Partially

If not, at which level and why:

Environmental Enhancements & considerations

Yes No Partially

If not, at which level and why:

Activity grading	Yes	No	Partially
If not, at which level and why:			
Review progress of intervention	Yes	No	Partially
If not, at which level and why:			
Collaboratively plan next stage of intervention	Yes	No	Partially
If not, and why:			
Medium intensity six weeks completed	Yes	No	Partially
If not, and why:			
One visit per week	Yes	No	Partially
If not, why:			
Therapeutic stance	Yes	No	Partially
If not, why:			
F. Review progress of intervention	Yes	No	Partially
If not, why:			
G. Collaboratively plan next stage of intervention	Yes	No	Partially
If not, why:			
Low intensity six weeks completed	Yes	No	Partially
If not, why:			
A. One visit per week	Yes	No	Partially
If not, why:			
Therapeutic stance	Yes	No	Partially
If not, why:			
C. Review progress of intervention	Yes	No	Partially
If not, why:			
D. Ask service users future goals	Yes	No	Partially
If not, why:			

### Acceptability Questionnaire

The intervention I carried out was acceptable to me	Yes	No
I would be willing to carry out this intervention again, in the future	Yes	No
I would suggest this intervention to other: staff and Service users	Yes	No
The intervention would not result in unhelpful or harmful effects	Yes	No
Overall, the intervention would be beneficial for people after leaving hospital	Yes	No

What components of the intervention do you think worked best?

In what way do you think they were effective?

What components of the intervention that you think were least effective?

In what way do you think these components were least effective?